

Family Views of End-of-Life Care in Acute and Community Hospitals

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1 Executive Summary

1.1 Introduction

The Hospice friendly Hospitals Programme (HfH) commissioned this study to assess the quality of end-of-life care in acute and community hospitals from the perspectives of bereaved relatives. A major rationale for the study was to develop and test methodology to survey bereaved relatives' views of end-of-life care that covers the HfH Programme themes of Integrated Care, Communication, Patient Autonomy and Design & Dignity. Another driver was to inform the set-up of a Nationwide Audit of End-of-Life Care (McKeown et al., 2010).

Study Aims

The overall aim of the study was to assess the quality of end-of-life care in two acute and two community hospitals from the perspectives of bereaved relatives. Study sub-objectives were to conduct a literature review to ascertain important ethical and methodological issues; to describe a census of deaths across study sites; to field test a survey instrument aimed evaluating the impact of the Hospice friendly Hospitals (HfH) Programme; to collect data about HfH Programme themes; and to establish if there were any differences in the pattern of results between acute and community hospitals.

Overview of the Hospice friendly Hospital's Programme

The HfH Programme is an initiative of the Irish Hospice Foundation and is a national programme aimed at implementing hospice principles into hospital practice. This five year programme was launched in Ireland in May 2007 and represents the first national end-of-life care initiative in Europe. The HfH Programme is being conducted in partnership with the Health Service Executive (HSE), Health Information and Quality Authority (HIQA) and a range of public sector and academic organisations.

The aims of the HfH Programme are to:

- Develop comprehensive patient focused standards for all hospitals in relation to dying, death and bereavement
- Develop the capacity of acute and community hospitals to introduce and sustain these standards

- Improve the overall culture in hospitals and institutions relating to death and dying.

To achieve these aims the HfH Programme is structured around standards development and capacity development, and focused around four key themes: Integrated Care; Communication; Design & Dignity and Patient Autonomy. Research and evaluation form a core part of programme's development and review.

1.2 Method

Ethical approval was received from the ethics committee of each participating hospital and from the Royal College of Surgeons in Ireland, Research Ethics Committee. Contact persons (the person listed on the deceased patient's file) (N=374) of deceased patients who had died over a one year period in the acute hospitals (N=2) and over a two year period in community hospitals (N=2) were invited to consent to receive the questionnaire by senior hospital personnel. Exclusion criteria included contact persons of patients who were dead on arrival to the hospital; who had died by suicide or who had spent less than twenty-four hours in the hospital. Other exclusions were contact persons who had been bereaved for less than four months.

Of those invited to consent to receive the questionnaire (N=374), 142 (38%) provided their consent. RCSI researchers sent those who had consented, the questionnaire and study information pack, which included information about bereavement supports. One hundred and eighteen questionnaire responses were returned, representing 83% of those who consented and 32% of the initial sample size (N=374).

Data was analysed using the statistical software package SPSS. The analysis identified high performance areas and opportunities for improvement across the acute and community hospital groups.

1.3 Key Findings

Key findings relevant to designing methods to evaluate end-of-life care, the census of deaths and family views of end-of-life care survey are provided next.

1.3.1 Designing methods to evaluate end-of-life care

Key findings which are helpful to consider in choosing methods to evaluate end-of-life care from the perspectives of bereaved relatives include:

Conducting postal surveys of bereaved relatives is an acceptable form of end-of-life care research in Ireland. This was evidenced by bereaved relatives' responses to the research. Almost 40% of those contacted consented to receive the questionnaire and of these 83.1% returned questionnaires. This is an important finding, prior to this study, no multi-site study in Ireland employed the use of postal questionnaires to evaluate end-of-life care in hospitals.

Patient, contact person and hospital factors had an impact on likelihood to consent to receive the questionnaire. Those who were more likely to consent to receive the questionnaire were contact persons of deceased males, female contact persons and contact persons of patients who died in community and not acute hospitals. For example, a higher number of contact persons of deceased males (40.9%) than of deceased females (35.1%) consented. The consent rate from female contact persons (n=209) was 45.5% compared to 28.4% from male contact persons (n=165). There was a higher consent rate from contact persons of deceased patients who died in community hospitals (44.2%) than from contact persons of those who died in the acute hospital group (31.1%). These findings are important as they create a profile of people whom are less likely to receive the questionnaire. The challenge for researchers and policy makers is to entice the range of profiles of potential respondents to participate in research.

In Ireland, longer time frames between bereavement and research contact may be preferable to most potential respondents.

In Ireland, studies have contacted bereaved relatives from time periods ranging from three months (McKeown et al., 2010) to at least one year (Keegan et al., 1999, St Vincent's Palliative Care Group, 2007). While the cited studies achieved comparable response rates, this study found that a higher proportion of contact persons bereaved for 13-18 months consented to receive the questionnaire than contact persons bereaved for 5-

12 months. While there is no set rule regarding the best time to contact bereaved relatives, from the point of view of achieving the maximum number of responses this study suggests that in Ireland perhaps longer time frames between bereavement and research contact are preferable to most potential participants.

1.3.2 Census of deaths

The research findings from the census of deaths indicated that hospital activities for death and dying differed between the acute and community hospital groups due to the types of services for death and dying these hospitals provide. The key findings were:

Providing care for sudden and traumatic deaths represented a significant proportion of hospital activity for death and dying in the acute hospitals surveyed.

While both hospital types cared for in-patient hospital deaths, the acute hospitals also provided care for deaths in Accident & Emergency and deaths external to the hospital. Of deaths in the acute hospital group, nearly two in three were of patients who were brought in dead to hospital (51%) or whom died in Accident & Emergency within twenty-four hours length of stay (12%).

Differences in patient age profile and length of last hospital stay suggests that the prognosis of dying may be more predictable in community hospitals and/or that community hospitals are more likely to be the last place of care for long term seriously ill and older patients.

When considering deaths in hospital after twenty-four hours length of stay, on average the acute hospital group provided end-of-life care to patients whom were younger than patients in the community hospital group and for whom had shorter lengths of stay than patients in the community hospital group. For example, two in three patients in the acute hospital group in comparison to nine in ten patients in the community hospital group were aged 75 years and over. Considering that the causes of death were similar across hospital groups, this finding suggests that the prognosis of dying may be more predictable in community hospitals and/or that community hospitals are more likely to be the last place of care for long term seriously ill and older patients. The differences in patient populations and in the length of last hospital stay may have implications for how these hospital types need to be supported and resourced in providing high quality end-of-life care to patients and their families.

1.3.3 Respondent views of end-of-life care survey

The Family Views of End-of-Life Care Survey evaluated elements of the structure, processes and outcomes of care. The outcomes evaluated were (i) respondent satisfaction with care and (ii) rating of the overall quality of care. The care structures and care processes evaluated were those associated with the four HfH Programme themes; patient autonomy, integrated care, communication and design & dignity. The key findings relevant to these are presented next.

Outcomes of Care

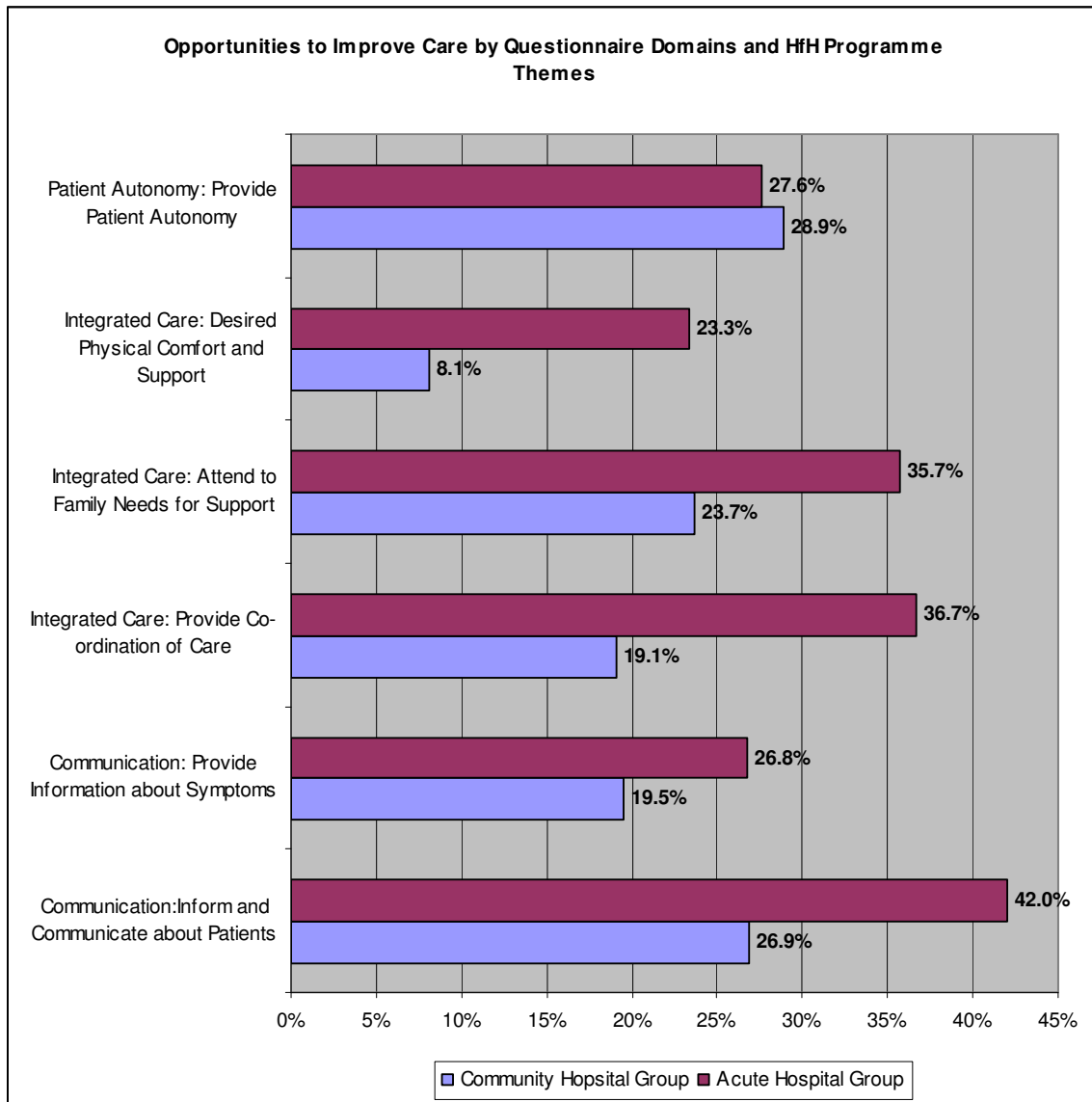
The overall satisfaction score for the community hospital group (44.7 out of 50) was higher than the score for the acute hospital group (40.6 out of 50). High performance areas (over 75% best rating (9 or 10) on satisfaction scale) across both groups were in relation to patient autonomy (*hospital team made sure patient died on own terms* and *hospital team respected the patient's wishes*). Low performance areas (less than or equal to 75% best rating (9 or 10) on satisfaction scale) in both groups were in relation to integrated care (*hospital team provided emotional support well*) and communication (*hospital team communicated well with patient and family*). The integrated care item, *hospital team made sure symptoms were controlled* was a low performance area in the acute hospital group but a high performance area in the community hospital group.

The rating of the overall quality of care and of care at the weekends was higher in the community hospital group than in the acute hospital group. Nearly two thirds (63.1%) of respondents in the community hospital group rated the overall care the patient received while in hospital as “excellent”, in comparison to 54.2% of respondents in the acute hospital group. While 50% of respondents in the community hospital group rated the way the hospital team responded to the patients needs in the evenings and weekends as “excellent”, the figure for this in the acute hospital group was 29.2%. These findings underlie the needs for improvements in the co-ordination of care, in particular within the acute hospital group.

Patient Autonomy

Respondents in the acute and community hospitals similarly rated whether the care provided was consistent with the patient's previously stated wishes with over 90% in both groups stating that this was the case. However, findings did demonstrate a need for increased discussion with patients and their families regarding wishes for medical treatment at end-of-life. The opportunity for improvement scores in the domain patient autonomy for the acute and community hospital group were 27.6% and 28.9% respectively (Figure 1).

Figure 1: Opportunities to improve care scores by questionnaire domain and hospital type



When considering choice of place for the patient to die, more respondents in the community hospital group (92.6%) than in the acute hospital group (76.0%) felt that the hospital was the right place for the patient to die given their needs in their final days. This finding suggests that interventions to facilitate patient and family preferences regarding the place for the patient to die may be more urgent in acute than community hospitals.

Integrated Care

Across all three integrated care domains, respondents in the community hospital group rated the care provided more highly than those in the acute hospital group. For the domain, *provide physical comfort and support*, the opportunity to improve score was 23.3% in the acute hospital group compared to 8.1% in the community hospital group. While across groups respondents similarly rated the provision of physical comfort for pain and trouble with breathing, the major discrepancy here was in relation to providing help for feelings of anxiety and sadness. The unmet need scores for help with feelings of anxiety and sadness were 51.9% in the acute hospital group and 15% in the community hospital group. From the point of view of emotional wellbeing and comfort, this represents a large discrepancy in the patient's experience of dying between acute and community hospitals.

This study's findings suggested that healthcare professionals in acute hospitals may be better positioned to respond to the emotional and support needs of families than of dying patients. The opportunities to improve care scores in the domain *attend to family needs for religious and emotional support* were 23.7% in the community hospital group and 35.7% in the acute hospital group. While there is scope for improvement in providing this type of care to families across both groups, findings in the acute hospital group showed considerable unmet need among dying patients for emotional support.

As with the previous integrated care domains, for the domain *provide co-ordination of care*, there was a higher opportunity to improve care score in the acute hospital group (36.7%) than in the community hospital group (19.1%). Across both groups however the highest opportunity to improve care was with regard to having one nurse identified as in charge of patient care.

Communication

Across the communication care domains, there were higher opportunities to improve care scores in the acute hospital group than in the community hospital group. These domains focussed on hospital staff communication with family members.

There was a higher opportunity to improve care score for the domain *inform and communicate about patients* in the acute hospital group (42.0%) than in the community hospital group (26.9%). Key areas for improvement included always keeping family members informed of the patient's condition and providing family members with information on the dying process. There was also a higher opportunity to improve care score for the domain *provide information about symptoms* in the acute hospital group (26.8%) than in the community hospital group (19.5%). The key area for improvement was in regard to providing information on pain management medication.

Other key findings related to the theme of communication included that across groups, of respondents who were told the patient was likely to die soon, the vast majority (91.2%) reported that this was done in a sensitive way. However, three in ten respondents reported that there was not enough privacy at this time. In addition, of respondents who felt "very prepared" for the death of the patient, 88.3% had been told by the hospital team that their relative was likely to die soon. This finding reinforces the importance of affording families the opportunity to understand what is happening to their ill relative so that they can adjust to their impending loss.

Another important finding was that across groups, approximately 40% of respondents reported that patients were aware that they were dying. However family members and hospital staff told the patient they were likely to die soon in less than 20% of cases across groups. These findings reflect a certain level of discomfort and ill ease in discussing death with dying patients and are perhaps linked to hospital and relative perceptions that most patients would prefer not to know when they are going to die.

Design and Dignity

Aspects of the design and dignity theme examined included the provision of dignity and respect, facilitating family presence at the time of death, availability of single rooms, the physical environment and hospital facilities. In contrast to the pattern of findings in

previous themes, respondents in the acute hospital group rated the availability of single rooms and the physical environment of the hospital more highly than respondents in the community hospital group. Key findings included that:

There were more opportunities to improve care in relation to the provision of dignity and respect in the acute hospital group than in the community hospital group. The important finding here was that two thirds of respondents in the acute hospital group indicated that the patients personal care needs were “always” taken care of as well as they should have been by the hospital team in comparison to 83.8% of respondents in the community hospital group.

While over 90% of respondents would liked to have been present at the time of death, approximately half were actually present at this time in the community hospital group and nearly two thirds were present in the acute hospital group. Difficulties associated with facilitating family preferences to be present at the time of death include the unpredictability of the time of death and the ability of relatives to arrive on time to the hospital. Opportunities for improvement were in relation to hospital staff arranging to facilitate family presence at the time of death. In the acute hospital group, approximately half of respondents (53.1%) reported that hospital staff asked them if they wished to be present at the time of death and this figure was nearly two thirds (63.6%) in the community hospital group.

Patients were more likely to die in a single room if they died in an acute hospital, one in three died in a single room in the acute hospital group, compared to one in five in the community hospital group. Qualitative findings suggested that when there was a lack of availability of single rooms at the time of death, this led to insufficient privacy and dignity for the patient and families and was distressing for other patients on the ward. Across groups less than one in four patients were offered a choice of room during their last hospital stay and one in three respondents were unaware of patient preferences at this time. Approximately 50% of respondents would have preferred if the patient had died in a single room. The findings demonstrate the need for hospital staff to have increased discussion with patients and families regarding type of room during the last hospital stay and at time of dying.

A higher proportion of respondents in the acute hospital group than in the community hospital group rated the *physical environment* of the hospital as excellent. This was in relation to space around the bed (by 16.8%), noise levels (by 18.2%), privacy (by 12.8%), temperature (by 4.4%) and natural light (by 5.4%). In contrast a higher proportion of respondents in the community hospital group than in the acute hospital group rated the *hospital facilities* as excellent in relation to availability of car parking for family (by 31.6%), availability of food for family (by 24.4%), chapel (by 12.8%), sleeping facilities for family (by 9.4%) and quiet place for family to go (by 5%). Given that this study was conducted across four hospitals, these findings can be seen as specific to the physical configurations and facilities available at these sites. Further research is required to see if these findings can be generalised across acute and community hospitals.

Interpretation of the Findings

Overall the findings showed that respondents in the community hospital group rated care more highly than those in the acute hospital group and specifically with reference to the themes of integrated care and communication. It needs to be taken into account that patient and respondent attributes may have impacted on these findings. The fact that patients tend to have a longer length of stay in the community hospitals (most common lengths of last hospital stay were 3-14 days (66.7%) in the acute hospital group compared to 1-6 months (56.9%) in the community hospital groups) may mean that patients have an increased chance of receiving good quality care as hospital staff have a longer time frame to become familiar with the patients' condition and their care needs. Relatives of patients have a longer time frame to establish rapport with hospital staff and to interact regarding patients' care needs. In addition, the age profile of respondents in the community hospital group was older than those in the acute hospital group and previous research has shown that older age groups are significantly more likely than others to be highly satisfied (Fakhoury et al., 1996). Therefore, both the length of last hospital stay and respondent age factors may mean that relatives of patients in community hospitals have a tendency to rate the quality of end-of-life care better than relatives of patients who died in acute hospitals.

1.3.4 Recommendations

Recommendations or areas to focus improvement efforts arising from the results of this study are outlined below.

Patient Autonomy

- Interventions to improve end-of-life care should promote the use of ethical frameworks that support hospital staff to become more informed, confident and collaborative in addressing the ethical and legal challenges that arise in the treatment of dying patients and their families. This will help patients, their families and hospital staff to generate discussion about these issues, so that patient and family preferences regarding end-of-life care can become known.
- Where possible hospital staff should aim to facilitate patient preferences for dying at home or within the healthcare setting of their choice.

Integrated Care

- Interventions to improve end-of-life should promote conceptualization of the patients and their families as the unit of care. Increased awareness of this will help reinforce a holistic approach to healthcare and help achieve better care outcomes.
- Greater awareness among hospital staff of how to meet patients' needs for help with anxiety and sadness while they are dying needs to be promoted. Activities may involve facilitating family presence, hospital staff being present with the patient themselves, facilitating patient and family privacy, allowing the patient opportunity to listen to music and facilitating patient opportunities to say goodbye to loved ones. This important topic also needs to be incorporated into the educational and training curriculums across the range of healthcare professionals.
- In terms of improving the co-ordination of care, interventions to improve end-of-life care should consider the use of integrated care pathways. The implementation of pathways support an interdisciplinary team approach to patient care and through accessible and auditable documentation support quality assurance mechanisms.

Communication

- The study's findings strongly reinforce the need for communication skills training specific to end-of-life care. Topics that need to be covered include the importance of sensitive and timely communication with both the patient and the family and the

importance of providing information to family members about the patient's condition and what to expect while the patient is dying.

- The study's findings also support the need for the use of ethical frameworks and protocols for communicating about particularly sensitive issues such as the patient's prognosis of dying. It is important that such tools do not compromise patient preferences not to be told their prognosis of dying.

Design and Dignity

- Given their association with better care outcomes, this study's findings provides further evidence for improving the physical environment of hospitals and usage of single rooms.
- The study findings reinforce the need for hospital staff members to implement protocols to ensure family presence at the time of death is facilitated.
- There is also a need to ensure family members visiting dying relatives have access to hospital facilities (such as car parking, food and sleeping facilities) to make their experience as comfortable as possible at this time.

Research

- Those aiming to evaluate care at the end-of-life should consider incorporating a mix of methodological approaches to incorporate the range of potential respondents to participate.
- From the point of view of achieving the maximum number of responses perhaps longer time frames between bereavement and research contact are preferable.

2 Literature Review

2.1 Introduction

This literature review was conducted to assist in the development and administration of a questionnaire to survey bereaved relatives' views of end-of-life care in acute and community hospitals in Ireland. The main aims of the review were to prepare the groundwork for survey development (Table 1) and to consider ethical and methodological concerns (Table 2).

Table 1: Survey Development Aims

To describe:
<ul style="list-style-type: none">• A conceptual framework that specifies and defines all relevant domains that are appropriate for describing and evaluating end-of-life care• Surveys used to obtain the views of bereaved relatives in empirical research and evaluation studies• Psychometric properties of survey instruments, their usage in different settings and samples, and methods of administration• Key results of studies that have used the survey instruments• Suitability of instruments for use in the evaluation of the HfH Programme.

Table 2: Ethical and Methodological Aims

To describe:
<ul style="list-style-type: none">• Validity of using bereaved relatives as proxies for the views of patients• Appropriate time frame, after bereavement, to contact relatives about participating in research• Appropriate time frame, from which to assess end-of-life care• Procedures for gaining access to next of kin information• Procedures for identifying the key informant most likely to know about the hospital care received by the patient and involved with their care• Procedures for avoiding and managing distress• Strategies to maximise response rates

This literature review describes the search strategy and details the literature review outcomes displayed in Table 3.

Table 3: Outcomes of Literature Review

- | |
|---|
| <ul style="list-style-type: none">• A conceptual framework detailing all relevant domains that are appropriate for describing and evaluating end-of-life care. This will detail the (a) patient factors affecting healthcare and outcomes of care (b) structure and processes of care and (c) outcomes of care.• A profile of surveys detailing the extent to which instruments measure HfH programme themes and end-of-life care domains as well as their psychometric properties, usage in different settings and samples, and methods of administration.• An evidenced-based assessment of the suitability of survey instruments or their subscales for use in the evaluation of HfH Programme.• A profile of similar study findings to assist in hypotheses definition for the larger scale audit of end-of-life care and for comparative and normative use.• Guidance on appropriate ethical and methodological approaches to conducting surveys of bereaved relatives |
|---|

2.2 Search Strategy

Evidence was collated from academic and grey literature.

Academic literature

The PubMed database was used to generate scientific studies. The MeSH combinations used included: surveys of bereaved relatives AND palliative care OR end-of-life care OR care of the dying OR post mortem care OR terminal illness OR terminal care OR bereavement care OR grief care. The titles of the articles identified were screened for inclusion in the review, if they pertained to:

- Palliative and/or end of life care
- Hospital setting
- Bereaved relatives
- Conceptual framework of end-of-life care
- Methodological and ethical issues in researching end-of-life care

Following this initial search it became apparent that five key authors (Addington-Hall, J; Teno, J; Lynn, J; Patrick, D; Costantini, M) had mainly published work relevant to the aims of the review. The full publications lists of these authors were then identified using PubMed. Abstracts were screened for inclusion if they described either a:

- Conceptual framework for end-of-life care,
- Retrospective studies and surveys of bereaved relatives about end-of-life care
- Methodology for and ethics of obtaining views of bereaved relatives.

The search timeframe in all cases was 1990 to 2007.

Grey Literature

Relevant websites and reports on end-of-life care were sourced.

2.3 Review

The outcomes of this review describe:

- A conceptual framework for describing end-of-life care
- Results of studies indicating what is important to measure about end-of-life care
- Key instruments measuring end-of-life care from the point of view of bereaved relatives including the QODD, FEHC, and VOICES
- Key research findings from national studies that have assessed end-of-life care from the point of view of bereaved relatives
- Methodology and ethical issues for researching end-of-life care.

2.3.1 Conceptual framework for evaluating end-of-life care

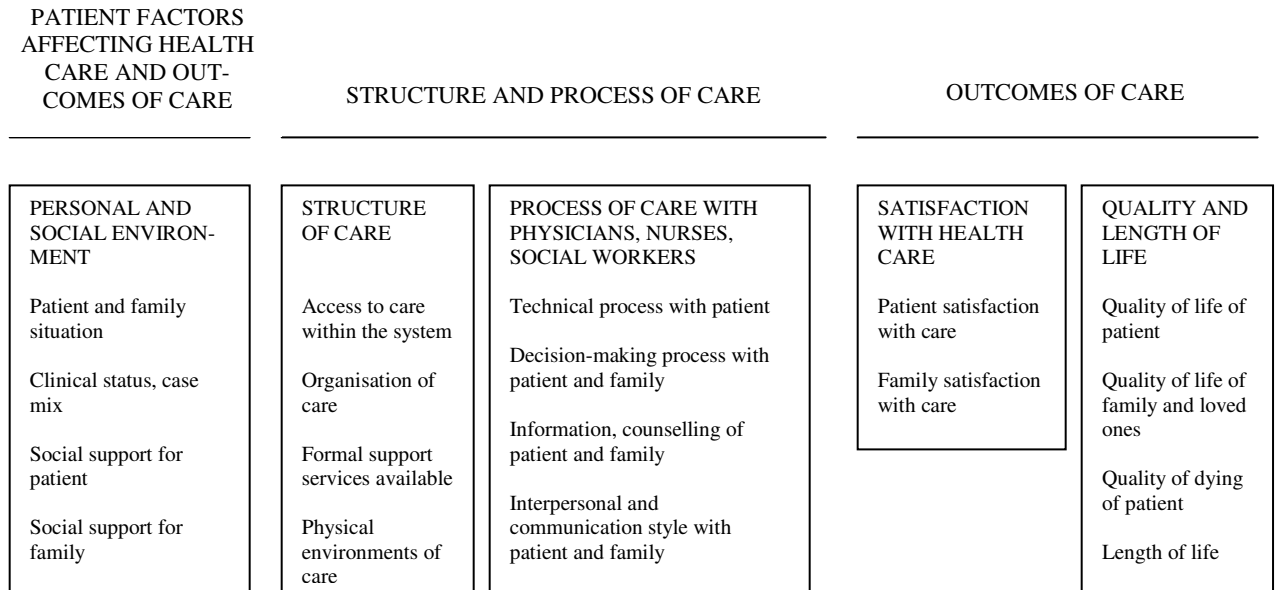
Based on a review of the literature, this section presents a conceptual framework of end-of-life care as a foundation from which to evaluate the HfH Programme. The goal of the HfH Programme is to improve the experience of death, dying and bereavement in Irish hospitals. It has become well recognised that key to improvement is measurement and that “if you can’t measure it, you can’t improve it” (Rudberg et al., 1997). Conceptual frameworks are very useful for planning how to inform and evaluate the care associated with a developmental end-of-life care such as the HfH Programme. The section defines (a) a general conceptual framework for end-of-life care (b) describes key framework outcomes and (c) considers whether these can be indicators of quality of care. These framework components provide options from which to focus the evaluation of the HfH Programme. Finally, the implications of research findings from studies of family views about what is important to measure about end-of-life are also considered.

2.3.1.1 Overview of a conceptual framework for end-of-life care

Understanding conceptual models for end-of-life care is very important particularly in the context of evaluation design. Conceptual models are inherent in the choice of survey instruments. As Byock (1999) has argued in choosing and applying any measurement tool, inextricably, a conceptual model (or set of models) and corresponding taxonomy are acquired.

Stewart et al (1999) conducted the first major attempt at describing a conceptual framework for end-of-life care for patients and families. All other models developed subsequently were modifications of this basis. Their framework specified and integrated indicators for evaluating the quality and outcomes of end-of-life care for patients and their families (Figure 2). The purpose of their framework was to facilitate the development of needed measures to assess components of the model. Instruments developed subsequently, measured only certain aspects of the framework. Measurement of the entire framework or all aspects of end-of-life care is beyond the scope of a single instrument.

Figure 2: Overall conceptual model of factors affecting quality and length of life of dying patients.



(Source: Stewart et al, 1999)

Based on a Donabedian model, the framework specifies three overarching categories (Stewart et al, 1999). These include (1) patient and family factors affecting healthcare and its outcomes, (2) the structure and process of care (from which to glean quality of care information) and (3) patient and family outcomes of care including satisfaction with care and quality and length of life. The elements of each category are detailed in Figure 2. A brief overview of the framework is outlined next.

Patient factors affecting healthcare and outcomes of care

The patients' personal and social environments are *patient factors that can affect the structure, process and outcomes of care*. Examples include patients' financial and clinical status in addition to the availability of social supports for patients and family. The latter can be considered as unmet needs that should be provided by the healthcare system (Stewart et al., 1999).

Structure and process of care

The elements of the *structure of care* affect the outcomes of care. For example, the site of death or the physical location of the patient during the dying process, and the site characteristics (e.g. aesthetics, noise, opportunities for social interaction) can strongly affect quality of life (Lawton, 1983; Lawton, 1989; Moss, 1996 cited in Stewart et al., 1999).

The framework authors perceive that the *process of care* may uniquely affect outcomes. Elements of the process of care include the technical process with the patient, the process of decision-making, information and counselling and interpersonal and communication style with the patient and family. The authors emphasise that the technical process also includes the continuity and coordination of care provided, which can be affected by the structure of care.

Outcomes of Care

The *outcomes of care* include satisfaction with healthcare both for the patient and the family and quality and length of life. Quality refers to quality of life of the patient, quality of life of family and loved ones and quality of dying of the patient.

This overview of the conceptual framework presents clear choices about how to evaluate the HfH Programme from the point of view of bereaved relatives. Instruments that have been developed since the establishment of this framework have focused on the structure and process of care (quality of care), quality of life or quality of death and dying as measures of the quality of end-of-life care. The HfH Programme Team can therefore choose one of these concepts as the focus of the evaluation. The choice concerns an instrument that directly measures the structure and process of care or one that measures the outcomes of care (quality of life or quality of dying and death). However, in all cases,

the foci of evaluation are not considered as direct indicators of quality of care.

Definitions of these particular framework concepts and an evidenced based assessment of the extent to which they act as quality of care indicators is presented next.

2.3.1.2 Framework outcomes: quality of care, quality of life, quality of dying and death

Although often amalgamated at the end-of-life, quality of care, quality of life, and quality of dying and death may be usefully distinguished (Patrick, Curtis, Engelberg, Nielsen, & McCown, 2003).

Quality of care

Quality of care at the end-of-life is distinguished from quality of life and of death by its emphasis on optimization of care and satisfaction with care (Heyland et al., 2006).

Steward et al. (1997) considered that quality of care variables [structure (e.g. care environment) and process (e.g. provider interpersonal and communication style) variables] are not and of themselves quality indicators. Rather, these variables must be evaluated in terms of whether they meet the standard criteria for quality or some may need to be evaluated in light of patient/family preferences. Evidently, measurement of quality of care requires a comprehensive set of standards and knowledge of patient preferences from which to interpret research findings.

Quality of life

Quality of life is a subjective construct, defined by the individual (Waldron et al., 1999).

The quality of people's lives is determined by the nature of their experiences and by the values and meaning they attach to them (Stewart et al., 1999). Quality of life at the end-of-life is distinguished from quality of care and of death by virtue of its emphasis on functional status or the fulfilment of needs essential to living even when a person is near death (Patrick et al., 2003). Since quality of life depends on the personal meaning assigned to one's current state, for those who are able to transcend their physical distress, quality of life can remain stable or even improve as physical suffering and disability increase (Stewart et al., 1999). When patients are nearing end-of-life report having a high overall quality of life, they may mean something very different than when those who are not in this phase report a high quality of life (Stewart et al., 1999).

Can quality of life be a quality of care indicator? Adler et al (1993) suggest that the magnitude of the effect of medical care on quality of life tends to be quite small (cited in Stewart et al., 1999). However, Stewart et al (1999) hypothesize that end-of-life care may have a much greater effect on quality of life. They argue that if their hypothesis is correct, the structure and process of care become points of intervention by which to improve quality of life. Cohen and Mount (1992) assert that for quality of life domains to serve as quality of care indicators, the domains must be able to be improved with optimal care (cited in Stewart et al., 1999). Therefore quality of life can be an indicator of quality of care to some extent. However, the existence of other determining factors makes establishing a casual relationship difficult.

Quality of dying and death

The Institute of Medicine (IOM) Committee on Care at the End of Life suggests that “a good death is one that is free from avoidable distress and suffering for patients and their families, in accord with the patients’ and families’ wishes, and reasonably consistent with clinical, cultural and ethical standards” (Field & Casey, 1997). The conceptual framework presented in this review defined the “quality of dying” as a personal evaluation of the dying experience including a subjective evaluation of patients’ expectations and values (Stewart et al., 1999).

Patrick et al (2001) further refined the concept of “quality of dying” to “quality of death and dying”. They operationalised a definition for the quality of death and dying as “the degree to which a person’s preferences for dying and the moment of death agree with observations of how the person actually died, as reported by others” (Patrick et al., 2001). The quality of death and dying is distinguished from the quality of care and of life by its focus on activities and emotions experienced if and when preparing for, facing and experiencing the final months or days of life and the moment of death (Patrick et al., 2003). Full measurement of this concept requires finding out patient preferences about dying and death before death, so that these can be compared with reports from family members or caregivers after death (Patrick et al., 2003). However, the authors acknowledge the difficulties of this endeavour. For example, they cite the IOM Report’s statement that patient preferences if possible to obtain, may also change prior to death and the stability of these preferences is important to establish. In addition, that dying

patients can be difficult to identify in advance of death, and the accuracy of the prognosis is limited, making reliance on patient preferences difficult (Field & Casey, 1997; Patrick et al., 2001).

Can quality of death and dying be an indicator of quality of care? Research studies have shown that quality of death and dying can be a measure of quality of care as higher quality of “*death and dying scores*” have been associated with aspects of the structure and process of care, including death in the location the patient desired, better ratings of symptom treatment and communication about treatment preferences (Curtis et al., 2002).

Each of these framework concepts have been itemized into a number of domains. These will be discussed in relation to the instruments developed to test them. Instruments that explicitly measure quality of life will not be assessed as these are considered least likely to demonstrate if changes in care practices have occurred and do not specifically assess the dying experience for patients and families.

2.3.1.3 Professional and family views about what is important to measure about end-of-life care

This section examines the significance of research studies examining family views about what is important to measure about end-of-life care for the integrity of conceptual frameworks of end-of-life care presented and for choosing a measurement tool to evaluate the HfH Programme from the point of view of bereaved relatives.

Consensus derived from expert opinion and confirmed through nationally representative surveys of patients, families, and providers has established standard domains to guide evaluation of end-of-life experiences (Hanson et al., 1997; Lynn et al., 1997; Singer et al., 1999; Steinhauser et al., 2000, 2001; Patrick et al., 2001; Patrick et al., 2003; Wenrich et al. 2003; National Consensus Project., 2004; Teno et al. 2004 cited in Mularski et al., 2007). Patients and families endorse essential concerns including the extent to which care addresses pain and other physical and emotional symptoms, advance care planning, continuity of care, spiritual well-being, practical support for care-giving and overall satisfaction. These concerns have been addressed by the general conceptual framework presented in this paper and therefore endorse its use as a conceptual tool in the evaluation of the HfH Programme. Critically the particular instrument selected for evaluation will

need to address these concerns. Instruments that address a range of these issues are reviewed in the next section.

2.3.2 Key measurement instruments used to obtain the views of bereaved relatives about end-of-life care

This section describes key instruments used to obtain the views of bereaved relatives about end-of-life care. The use of these instruments reflects that psychometric measurement of the structure, process and outcomes of care is a valuable way to improve end-of-life care (Morita et al., 2004). The instruments listed in Table 4 measure certain components of the framework and some overlap to measure two or more aspects of the framework. This review will focus solely on the QODD, FEHC, and VOICES measurement instruments as cursory review has suggested these may be most suitable for use in the evaluation of the HfH Programme.

The description of the instruments will refer to the purpose for which the instrument was intended, its psychometric properties, usage in different settings and samples and methods of administration. A selection of key results of studies that have used the survey instruments will be presented in addition to a detailed assessment of the suitability of the instruments for use in the evaluation of the HfH Programme.

Table 4: Key instruments used to obtain the views of bereaved relatives

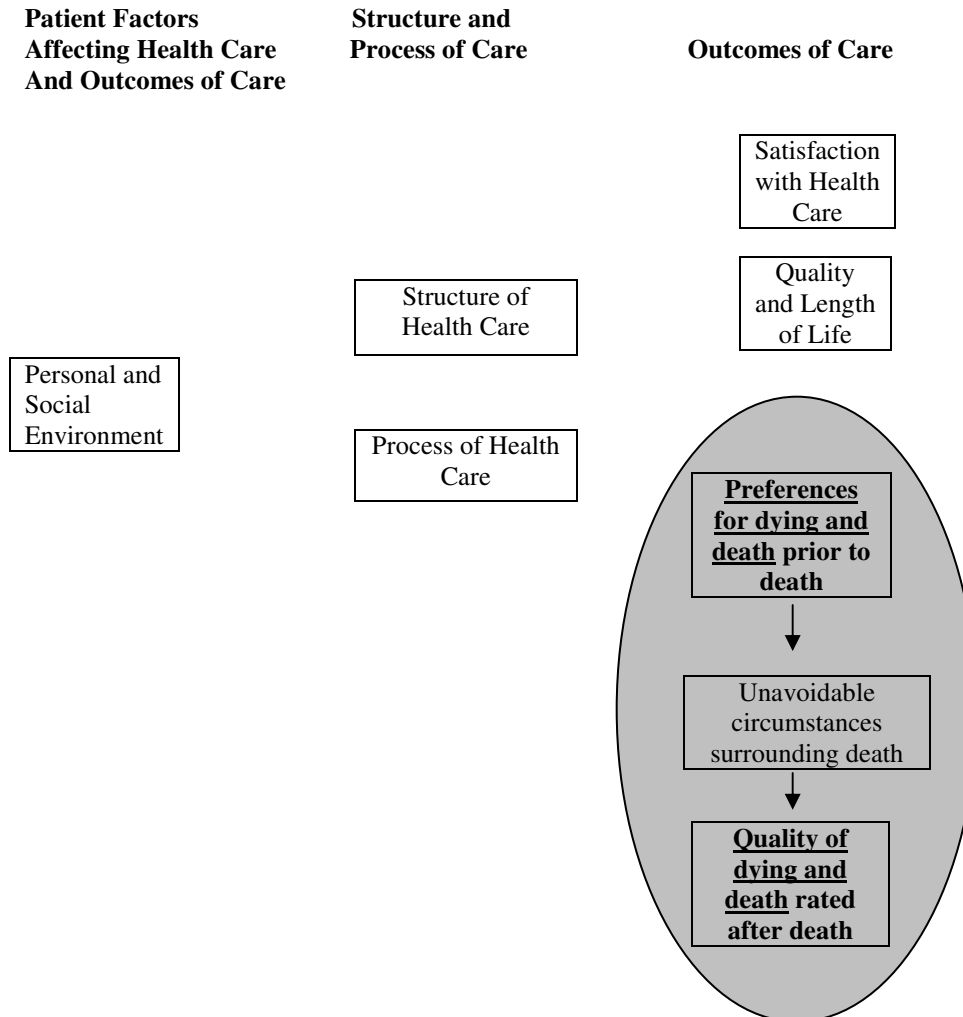
Component of Conceptual Framework for End-of-Life Care	Measurement Tool
Quality of Life	Quality of Life at the End of Life (QUAL-E) Quality of Dying and Death (QODD)
Quality of Death and Dying	Quality of Dying and Death (QODD) Toolkit of Instruments to Measure End-of-Life Care (TIME)
Satisfaction with Care	FAMCARE scale Satisfaction scale for the Bereaved Family receiving Inpatient Palliative Care (Sat-Fam-IPC) Quality of End-of-Life Care and Satisfaction with Treatment (QUEST)
Quality of the structure and process of care	Care Evaluation Scale (CES) Toolkit of Instruments to Measure End-of-Life Care (TIME)* Quality of End-of-Life Care and Satisfaction with Treatment (QUEST)* Family Evaluation of Hospice Care (FEHC) Views of Informal Carers – Evaluation of Services (VOICES)

(Source: adapted from Morita, Hirai et al, 2004)

2.3.2.1 Quality of Death and Dying (QODD) Instrument

Researchers at the End of Life Care Research Program at the University of Washington developed the 31-item QODD instrument. It was developed for completion after death by family members or clinicians (Levy et al., 2005). Studies have administered the QODD to family members by face to face or telephone interview. Clinicians surveyed have self-administered the questionnaire. The QODD is based on a conceptual model for end of life care (Figure 3) and the operational definition of quality of dying and death, created by Patrick et al (2001).

Figure 3: Conceptual model for measuring quality of dying and death (contained in the shaded oval) and its place in the overall conceptual model of factors affecting quality of dying patients and their families.



Source: (Patrick et al., 2001)

The intended use of the QODD is in evaluating the process of end-of-life care (Patrick et al., 2001). The next section describes the instrument, including its development and psychometric properties. It also describes research studies that have used the QODD instrument and assesses its suitability for use in the evaluation of the HfH Programme.

2.3.2.1.1 Development of the QODD Instrument

The development of this instrument and underlying conceptual model involved five steps including (a) a review of previous studies of the dying experience, (b) qualitative interviews with patients defining domains of dying and death, (c) a review of the authors' previous research, (d) a review of the quality of life instruments for people with terminal illness that covered domains bridging quality of life at the end-of-life and quality of dying and death and (e) assuring the instrument had desirable measurement properties. Among

these desirable properties were a clearly identified domain structure for instrument development, concepts and language used by patients and families, the expression of concerns most important to individual patients at the end-of-life as well as a standardised measure that could be used across persons. Other desirable properties included an instrument that was cognizant of the different dying trajectories and of the views of various stakeholders (Patrick et al., 2001).

2.3.2.1.2 Description of the QODD Instrument

The QODD instrument was developed in six conceptual domains (Table 5). The QODD is an interviewer-administered questionnaire containing 31 items requesting the respondent to rate the quality of the dying experience for the decedent's last seven days or, if the patient was unconscious or unresponsive during the last seven days, over the last month before death (Curtis et al., 2002).

The family QODD has two parts to each question. Part A asks for the frequency with which an experience occurred over the last week of life. For some experiences (e.g. having pain under control, breathing comfortably, being able to feed oneself) families use a 0 to 5 scale (0, none of the time; 1, a little bit of the time; 2, some of the time; 3, a good bit of the time; 4, most of the time; 5, all of the time) and for other experiences (e.g. having funeral arrangements in order, having a religious ceremony before dying, having discussed wishes for end-of-life care with doctor), families indicate "yes" or "no". Part B of each question asks respondents to rate the quality of each experience on a 0 to 10 scale, with a score of 0 designating a "terrible experience" and 10 an "almost perfect experience" (Levy et al., 2005). The questionnaire also includes some basic demographic questions, and questions that examine information about the conditions surrounding a death (Mularski et al., 2005). The number of these questions vary according to the version of the instrument used. These can include date and place of loved-one's death; how many hours were spent visiting with the decedent; how often the respondent had seen the decedent in the last year; how long before the decedent's death the respondent thought the person was aware they were dying, whether or not the respondent could talk with the decedent in the last seven days of life in a way they could understand; respondent's relationship to the decedent; how far away the decedent lived from the respondent; the gender of the respondent; the race/ethnicity of the respondent; and the educational level of the respondent.

Table 5: Specific Items in the QODD Instrument Organized by Conceptual Domains

31-Item QODD Instrument	23-item ICU QODD Instrument
Symptoms and Personal Care	Symptoms and Personal Care
1. Having pain under control	1. Having pain under control
2. Having control over what is going on around you	2. Having control over what is going on around you
3. Being able to feed oneself	3. Being able to feed oneself
4. Having control of bladder, bowels	
5. Being able to breathe comfortably	4. Being able to breathe comfortably
6. Having energy to do things one wants to do	
Preparation for Death	Preparation for Death
1. Feeling at peace with dying	1. Feeling at peace with dying
2. Feeling unafraid of dying	2. Feeling unafraid of dying
3. Avoiding strain on loved ones	
4. Having health care costs covered	3. Having health care costs covered
5. Having visits from a religious leader	4. Having visits from a religious leader
6. Having a spiritual service or ceremony before death	5. Having a spiritual service or ceremony before death
7. Having funeral arrangements in order	6. Having funeral arrangements in order
8. Saying goodbye to loved ones	7. Saying goodbye to loved ones
9. Attending important events	
10. Clearing up bad feelings	8. Clearing up bad feelings
Family Concerns	Family Concerns
1. Spending time with spouse/partner	1. Spending time with family/friends
2. Spending time with children	2. Spending time alone
3. Spending time with family/friends	
4. Spending time alone	
5. Spending time with pets	
Treatment Preferences	Treatment Preferences
1. Discuss end-of-life wishes with your doctor	1. Discusses wishes for end-of-life care
2. Being on a ventilator or dialysis	2. Being on a ventilator
3. Have the means to end life if desired	3. Being on dialysis
Whole Person Concerns	Whole Person Concerns
1. Being able to laugh and smile	1. Being able to laugh and smile
2. Being touch and hugged	2. Being touch and hugged
3. Finding meaning and purpose	3. Finding meaning and purpose
4. Keeping one's dignity and self-respect	4. Keeping one's dignity and self-respect
Moment of Death	Moment of Death
1. Dying in the place of one's choice	
2. Dying in the state of one's choice (i.e. asleep, awake, unconscious)	1. State at the moment of death
3. Having desired people present at the time of one's death	2. Having family present at the moment of death

Source: Adapted from (Curtis et al., 2002; Mularski et al., 2005)

Based on the initial QODD instrument, a 23 item Intensive Care Unit (ICU) QODD was developed. The 23 items (Table 5) were chosen based on face validity for items having relevance for deaths occurring in the ICU and by examining non-response patterns for ICU deaths (Mularski et al., 2005). The ICU QODD asks respondents to rate the quality of the dying experience for the decedent's last several days.

2.3.2.1.3 Analysis of QODD Data

Analysis of QODD data enables the assignment of a number to reflect the quality of death and dying. A QODD score is calculated based on the quality rating component of questions and does not include the frequency component. The score is based from 1 to 100 and can form the primary outcome basis for all analysis (Mularski et al., 2005). For example, it is possible to examine the components of an end-of-life care experience associated with a higher QODD score. Patrick et al (2001) state that this approach can be viewed as the ultimate form of reductionism, but argue that it is not their intention to define all that dying means or might possibly mean, as this can be only known to the individual. Rather it is their intention to apply humanistic thinking and measurement principles to end-of-life experiences to obtain a summary measure that can be applied to populations and used to improve end-of-life care.

2.3.2.1.4 Validation of QODD Instrument

The family assessed QODD instrument has shown some evidence of validity in a study of 204 deaths in Missoula County, Montana and was shown to have good internal consistency (Cronbach alpha = 0.86) and construct validity, correlating significantly with measures of symptom burden, patient-clinician communication about treatment preferences and quality of care (Levy et al., 2005). The deaths assessed occurred in different care settings including hospitals (Curtis et al., 2002). The ICU QODD has also been validated in two studies (Hodde et al., 2004; Mularski et al., 2005). The instrument showed moderate interrater reliability when compared by two to four family members and high internal consistency (Cronbach alpha = 0.96) when used by ICU nurses. The methods and findings from research studies using the QODD are outlined next.

2.3.2.1.5 Research studies using the QODD instrument

Montana Study

The Montana Study identified clinical correlates of a high quality death. The instrument was administered to family members of patients who died in Missoula in 1996 and 1997 (Curtis et al., 2002). Respondents were part of the Missoula Demonstration Project (MDP), a community-based research and community engagement programme whose mission is to improve quality at life's end.

This study used funeral records from the four funeral homes in Missoula County, to identify deaths (n=1082) occurring in the county in 1996 and 1997 and the primary and secondary contact for each decedent. These years were chosen to precede interventions by the MDP. Excluding those who had participated in a pilot, 935 deaths were eligible to participate in study. Primary contacts were sent a letter and then telephoned to ask if they, or one of their other family members would like to participate in a face-to-face interview. If agreement was achieved over the telephone, an interview was scheduled and written informed consent was obtained prior to the interview. All interviews were carried out between 1 and 3 years after the death (mean = 708 days, range = 305 – 1035 days). Of 935 decedents' next of kin, 440 (47.1%) declined participation and 243 (26.0%) could not be reached due to an incorrect address or phone number. The remaining 252 (27.0% of total sample; 36.4% of those contacted) family members consented to participate and completed an in-person interview. Exclusions were sudden deaths (n=45) and decedents who were less than 18 years old (n=2). These exclusions left 205 decedents who had a family member complete an in-person interview that included the QODD instrument (Curtis et al., 2002).

In this study, QODD scores ranged from 26.0 to 99.6, with a mean of 67.4. Results showed that the total QODD score was not associated with patient age, sex, education, marital status, or income. Higher QODD scores were significantly associated with death at home ($P < 0.01$), death in the location the patient desired ($P < 0.01$), lower symptom burden ($P < 0.001$), and better ratings of symptom treatment ($P < 0.01$). While the total score was not associated with the presence of an advance directive, higher scores were associated with communication about treatment preferences ($P < 0.01$), compliance with treatment preferences ($P < 0.001$), and family satisfaction regarding communication with

the health care team ($P < 0.01$). Accessibility of a health care team member at night or on weekends was also associated with a higher QODD score ($P < 0.001$). There was also a lack of association between the intensity of care received during the last month of life and scores on the QODD. While there was a trend toward more invasive treatment being associated with poorer quality of dying and death, this trend did not meet the threshold for statistical significance. The QODD total score demonstrated good cross-sectional validity. It is noteworthy that, in addition to the QODD questions, the authors asked respondents two global questions rating the quality of life in the last seven days and the quality of the moment of death. These were significantly associated with the QODD total score; both questions combined explained 38% of the variance in the QODD total score (Curtis et al., 2002).

Seattle Study

The 31-item QODD was applied in a hospice sample in Seattle, Washington (Patrick et al., 2003). Ninety-six patients and their family members or loved ones were recruited. Among 309 eligible individuals, 189 (61%) patients or family members declined to participate. Of the 96 patients enrolled, 79 have died and 62 family members completed the QODD. The survey was completed on average of 3 months after a patient's death. Higher QODD scores were associated with reports of satisfaction with the amount of time providers spent with patients, how often providers explained treatments, how often treatment plans were followed, better ratings of care, quality of life during last days, and moment of death (Patrick et al., 2003).

ICU QODD Studies

The ICU QODD has been applied exclusively in hospital settings. For example, Mularski et al (2005) explored the quality of the dying experience and associations to higher quality ratings for people who died in an ICU. The methodology was a retrospective design using medical record review and surveys of family members using the ICU QODD instrument. The surveys were administered by face to face interview. The study site was four ICUs affiliated with a university and a Veterans Affairs Medical Centre in the USA. All deaths in the year 2000 were reviewed for inclusion in the study. Inclusion criteria were that decedents were at least 21 years old at the time of death and died in the ICU after a stay of 3 days. Family members were contacted between 4 months and 1 year after their bereavement. Two to four family members who were themselves at least 21

years old and had visited a minimum of six hours in the ICU before their loved-one's death were identified for each decedent. All family members gave written informed consent and the study received approval from Institutional Review Boards. The participants were 94 family members of 38 ICU decedents.

Research results included that family members reported that symptoms were poorly controlled. For example, pain under control most or all of the time in 47%, and breathing comfortably most or all of the time in 3% of patients. Families expressed a moderate and variable view of the quality of dying – an overall ICU QODD score of 60 +/- 14 [mean +/- SD]. Higher ICU QODD scores were associated with control of pain ($r = 0.42$, $p = 0.009$), control of events ($r = 0.62$, $p < 0.001$), a “preparation for death” aspect of the dying experience - feeling at peace with dying ($r = 0.69$, $p < 0.001$), and a “whole-person concern” - keeping one's dignity and self-respect ($r = 0.50$, $p < 0.001$) (Mularski et al., 2005). The authors concluded that after adjusting for symptom and personal care scores, certain whole-person and preparation-for-death components of the dying process, and not aggressiveness of end-of-life care, remained the most associated to quality ratings. The study suggests that care at the end of life in the ICU includes not only managing pain, but also supporting dignity, respect, and peace, and maximizing patient control (Mularski et al., 2005).

The ICU QODD was also applied in a study that compared perceptions of the quality of dying and death in the ICU across nurses, resident physicians, attending physicians, and family members (Levy et al., 2005). The study design was a cross sectional survey of family members and ICU clinicians following the death of enrolled patients in two medical ICUs at academic tertiary care medical centres. Inclusion criteria for patient deaths were those who were admitted to the ICUs during the study interval from February to June of 2000 and who died during their stay. Patient deaths with an ICU length of stay of less than 48 hours were excluded as were those where only one of three clinicians were available to complete the QODD. Family members were identified from the hospitals records as the emergency contact person. Approval for the study was received from the Institutional Review Boards at both hospitals and written informed consent was obtained from family members at the time the patients were admitted to ICU. Within 24 hours of the death, the clinicians caring for the patient were given a self-administered version of the QODD. One month after the patient's death, a family member was contacted and the

QODD was administered by telephone. During the study 141 patient deaths were screened and 68 patient deaths were evaluated. In a very small number of cases (n=3), the primary physician requested that the family not be interviewed. The QODD was completed by a family member for 50 deaths, representing a 55% response rate for eligible deaths.

Research results included that family members and attending physicians gave the most favorable ratings of death, while nurses and residents provided less favorable ratings. Significant differences between these groups were notable ($p < 0.01$) on items related to patient autonomy: maintaining dignity, being touched by loved ones, and the overall quality of death. The authors' discussion of the findings highlighted that different types of respondents evaluated the QODD differently. They believe that the variability may represent measurement error or "noise" in the instrument or "real differences" in the ratings of the same patient's death. Real differences can be due to observations made because different raters were at the patient's bedside at different times and for differing time periods witnessing different events (observed differences), or differences in perceptions of the same events due to the raters' prior experiences, training or relationship with the patient (perceived differences). This is perhaps an unavoidable limitation of assessments of the dying experience after death. However, the authors did allude to the clinical implications of the findings. This may involve finding out perceptions regarding quality of care from all clinicians on daily ICU rounds. They state that an understanding of each team members' perception of the dying process may improve the clarity of goals of care and the overall plan of care to achieve co-ordination in information passed on to patients and their families (Levy et al., 2005).

2.3.2.1.6 Assessment of suitability of QODD for use in the evaluation of the HfH Programme

The suitability of the QODD for use in the evaluation of HfH Programme is assessed next. The criteria for evaluation are the:

- extent to which the QODD measures HfH Programme themes
- psychometric properties of the QODD
- extent to which the QODD measures outcomes relevant to patients and families
- scope for further use of the QODD in the evaluation of the HfH Programme

- QODD foci of evaluation.

The ICU QODD version is assessed in these regards as it has been labelled as suitable for use in generic hospital settings.

QODD Measurement of HfH Programme Themes

The ICU QODD domains assess three out of the four HfH Programme Themes:

- The HfH theme of integrated care is assessed by 21 items across all seven QODD domains and the two global quality of care items. The particular sub-themes of integrated care assessed include symptom experience (n=4), symptom control (n=3), psycho-social supports (n=5), spiritual well-being (n=6), healthcare costs (n=1) and quality of care (n=2). However, the questions do not address the sub-themes of continuity of care, grief and bereavement. Absence of these items is a common gap across measurement instruments (Mularski et al., 2007).
- The HfH theme of patient autonomy is assessed by 2 items across the domains of preparation for death and treatment preferences. The sub-themes of patient autonomy assessed include advance care planning -funeral arrangements and advance care planning - treatment preferences.
- The HfH theme of design and dignity is addressed by 1 item under the domain of whole person concerns. The sub-theme assessed is personal dignity.
- The theme of communication is not assessed by this version of the QODD. Therefore important sub-themes not assessed include communicating bad news, and information about the patient's condition, treatment and about family supports. The QODD instrument developers have not developed an instrument assessing the quality of communication from the point of view of bereaved relatives. However, the Quality of Communication (QOC) instrument is a patient-report interviewer administered questionnaire (13-item) available for assessing the quality of communication. General communication skills and communication about end of life care are assessed (Engelberg et al., 2006).

QODD psychometric properties

The psychometric properties of the QODD have been discussed with reference to the validation studies. A recent review of measures of end-of-life care and its outcomes praised the QODD on the basis of its conceptual grounding, psychometric evaluation and acceptance in the field of palliative medicine (Mularski et al., 2007).

Scope for further use of the QODD in evaluation of HfH Programme

One benefit of the QODD is that it has been designed for completion by family members and a range of healthcare professionals. Further use of this instrument in populations beyond family members can facilitate a stakeholder analysis of the dying experience. Use of the QOC would involve patients who are nearing end-of-life in the evaluation of the programme. This approach identifies the range of views necessary for improving patient care.

QODD measurement of outcomes relevant to patient and family experiences

One disadvantage of using the QODD is that all questions are aimed at assessing patients' experiences of death and dying as an indicator of the quality of care. No questions assess the care received by family members.

QODD foci of evaluation

The QODD foci of evaluation are on the quality of death and dying. Patrick and Engelberg et al (2001) state that this facilitates a focus on the features of a good or a bad death that are distinct from the important features of quality of life at the end-of-life. They believe that separate measurement of these concepts are a major step in identifying and evaluating interventions that will improve the dying process. From this perspective it is important to consider the type of findings use of the QODD will generate. From the studies reviewed, it is possible to hypothesise for example that use of the QODD may prove or disprove that:

- QODD scores were not associated with patient factors such as age, sex, education, marital status or income. If proven, this will aid the task of demonstrating the impact of the programme separate from the impact of external factors.
- QODD scores were associated with quality of life in the last several days of life and quality in the moment of death. If proven, and if scores improve on a time series basis, this will help demonstrate the impact of the programme.

The practical use of findings such as these will show the extent to which patients' and families' care experiences are amenable to change by a healthcare intervention – for example do patient characteristics or care practices determine QODD scores? The aspects of the structure and process of care found to be associated with poor quality QODD scores will highlight areas for improvement. If the QODD instrument were to be used on

a time series basis it may be able to detect change in outcomes due to change in care practices.

However, the approach taken by the QODD however, has been criticised for its focus on the measurement of outcomes as a quality indicator. It has been stated that outcomes can be influenced by various patient- and family- related factors that healthcare providers cannot change (Morita et al., 2004). The critics believe that using this approach can in some cases make extrapolating areas of care perceived as requiring improvement difficult. For example, relatives of patients who experienced existential suffering might think this is not the responsibility of healthcare professionals (Morita et al., 2004).

However Patrick et al (2003) state that it is impossible to completely separate quality of care, as included in evaluations of treatments, from quality of life at the end-of-life or quality of dying and death. They ask the question, if a loved one reports after death that he or she was happy with the care a dying patient received after death, is the death reported of higher quality? They believe that confounding between treatment and outcomes makes causal explanations for observed results difficult but does not necessarily complicate the ultimate goal of improving quality of care to improve the quality of dying and death (Patrick et al., 2003).

In summary, the QODD is useful in identifying correlates of a good death and can be an effective way to evaluate an intervention programme. The advantages of using it in the evaluation of the HfH Programme include its applicability to the theme of integrated care, its sound psychometric properties and its scope for use with healthcare providers and in a stakeholder analysis of the dying experience. It also permits the formulation of a quality of death and dying score, which is a useful way of monitoring change in outcomes. Disadvantages include its sparse measurement of the themes of patient autonomy and dignity and design, and its lack of measurement of the communication theme. It also doesn't measure the care received by families and has not previously been administered by postal format to bereaved relatives.

2.3.2.2 Family Evaluation of Hospice Care

The FEHC instrument was developed by Professor Joan Teno and researchers at Brown University in conjunction Stephen O'Connor, PhD, vice president of the National Hospice and Palliative Care Organisation (NHPCO). The instrument is based on a conceptual model of patient-focused, family centred medical care, which focuses on the patient but also acknowledges the importance of the family in care of the dying (Connor et al., 2005). Under this model, a health provider offers excellent end-of-life care when it 1) provides the desired physical comfort and emotional support, 2) supports shared decision-making, 3) treats the patient with respect, 4) attends to the needs of the family for emotional support and the needed information and 5) co-ordinates care effectively (Teno, Casey, Welch, & Edgman-Levitan, 2001). The instrument has been available for use since 2003.

2.3.2.2.1 Development of the FEHC

Connor et al. (2005) state that the FEHC was based on the After Death Bereaved Family Member Interview, which was developed to examine whether end-of-life care met the expectations and needs of dying patients and their families. The After Death Bereaved Family Member Interview was developed based on systematic review of guidelines, views of professionals in end-of-life care and focus groups on dying persons, their relatives and friends (Connor et al., 2005). This survey has been used in the USA in a 22 state study of dying (Teno et al., 2001). The FEHC is a shortened version of this questionnaire and contains key outcomes measures of the After Death Bereaved Family Member Interview conceptual basis without some of the descriptive questions.

2.3.2.2.2 Description of the FEHC Instrument

The FEHC survey contains 61 closed-ended questions that are grouped into domains that can be administered separately and while preserving psychometric integrity (Mitchell et al., 2007). The FEHC was developed in three primary domains with an additional domain that addresses three common symptomatic concerns. The three primary domains are 1) attending to family needs for support, 2) attending to family needs for information, and 3) co-ordination of care. The fourth domain (provide desired physical comfort and emotional support) asks the family for their surrogate assessment of whether there were unmet needs regarding pain management, dyspnea management and emotional supports

for the patient (Connor et al., 2005). A list of the key domains and corresponding items are listed in Table 6. There are two versions of the FEHC, one contains core questions (44 items) and the other contains the complete 61 items. The 61 item questionnaire includes optional modules such as advance care planning, self-efficacy of the family, equipment and pharmacy and overall satisfaction with care (ratings of domains of care).

Several types of question response sets examine the key domains. Unmet needs are examined using questions with responses such as whether the patient received “less than wanted”, “right amount” or “more than wanted” treatment of symptoms while dying. The respondent’s confidence in important tasks in care of a dying patient are examined with questions that ask whether they were “very confident”, “fairly confident” or “not at all confident”. For the majority of questions, a most desirable answer is identified. For example, the most desirable answer for the question of how much help in dealing with his/her breathing the patient received while under the care of the hospice is “right amount”. If the respondent considers any other answer, this is considered a negative response or “an opportunity for improvement”. Two types of rating questions are used, one asks the respondent to assess an aspect of end-of-life care using a 0 – 10 response task, where 0 is worst possible care and 10 is best possible care. The second asks the respondent to assess the overall quality of care using an “excellent” to “poor” rating scale (Connor et al., 2005).

Table 6: Summary of FEHC Questions Comprising Domain Scores

Domain	Questions Comprising Domain Score
Attending to family needs for support	<ul style="list-style-type: none"> Did any member of the hospice team talk to you about your religious and spiritual beliefs? (yes/no) Did you have as much contact of that kind as you wanted? (yes/no) How much emotional support did the hospice team provide to you <u>prior</u> to the patient's death? (less than was wanted/right amount/more than was wanted) How much emotional support did the hospice team provide to you <u>after</u> the patient's death? (less than was wanted/right amount/more than was wanted)
Attending to family needs for information	
Patient's condition and what to expect	<ul style="list-style-type: none"> How often did the hospice team keep you or other family members informed about the patient's condition? (always/usually/sometimes/never) Did you or your family receive any information from the hospice team about what to expect while the patient was dying? (yes/no) Would you have wanted more information about what to expect while the patient was dying? (yes/no)
Medications and treatments for symptoms	<ul style="list-style-type: none"> Did you or your family receive any information from the hospice team about the medicines that were used to manage the patient's pain? (yes/no) Did you want more information than you got about the medicines used to manage the patient's pain? (yes/no) Did you or your family receive any information from the hospice team about what was being done to manage the patient's trouble breathing? (yes/no) Did you want more information than you got about what was being done for the patient's trouble with breathing? (yes/no)
Family's confidence in the provision of care to the dying person	<ul style="list-style-type: none"> How confident did you feel about doing what you needed to do in taking care of the patient? (very confident/fairly confident/not confident) How confident were you that you knew as much as you needed to about the medicines being used to manage the patient's pain, shortness of breath or other symptoms? (not confident/fairly confident/very confident) How confident were you that you knew what to expect while the patient was dying? (very confident/fairly confident/not confident) How confident were you that you knew what to do at the time of death? (very confident/fairly confident/not confident)
Coordination of care	<ul style="list-style-type: none"> How often did someone from the hospice team give confusing or contradictory information about the patient's medical treatment? (never/sometimes/usually/always) While under the care of hospice, was there always one nurse who was identified as being in charge of the patient's overall care? (yes/no) Was there any problem with hospice doctors or nurses not knowing enough about the patient's medical history to provide the best possible care? (yes/no)
Provision of desired physical comfort and emotional support	
Unmet need – pain	<ul style="list-style-type: none"> How much medicine did the patient receive for his/her pain? (less than was wanted/right amount/more than was wanted)
Unmet need – dyspnea	<ul style="list-style-type: none"> How much help in dealing with his/her breathing did the patient receive while under the care of hospice? (less than was wanted/right amount/more than was wanted)
Unmet need – emotional support	<ul style="list-style-type: none"> How much help in dealing with these feelings did the patient receive? (less than was wanted/right amount/more than was wanted)
Overall Satisfaction	<ul style="list-style-type: none"> How well did the hospice team do at providing end-of-life medical care that respected the patient's wishes? (0=worst care through 10=best care) How well did the hospice team communicate with the patient and his/her family about the illness and the likely outcomes of care? (0=worst care through 10=best care) How well did the hospice team make sure that the patient's symptoms were controlled to a degree that was acceptable to him/her? (0=worst care through 10=best care) How well did the hospice team make sure that the patient died on his or her own terms? (0=worst care through 10=best care) How well did the hospice team do at providing emotional support for you and the patient? (0=worst care through 10=best care)

Source = (Connor et al., 2005)

2.3.2.2.3 Analysis of FEHC Data

Each domain has a number of questions that comprise a domain score. Problem scores and a modified domain score are calculated (Teno and Clarridge, 2001 cited in Connor et al., 2005) as follows:

- To calculate the problem scores, each question (except questions use a rating task) is assigned one “desirable answer” and all other answers are considered to be “negative responses”. Problem scores total the negative responses to the individual questions within that domain. A high problem score indicates more opportunities to improve care.
- A domain score is an average of the responses of the items that compose a problem score.

For example, the domains scores for *attending to family needs for support* domain, the *co-ordination of care* domain, and the *patient’s condition and what to expect* and *medications and symptoms for treatment* sub-domains are calculated by summing the negative responses to individual questions. The *family’s confidence in the provision of care to the dying person* sub-domain is rated from not confident (scored a 1) to very confident (scored a 3). Questions are totaled to derive a score from 3 to 12. For the *provision of desired physical comfort and emotional support* domain, unmet need scores represent the percent of surveys that indicated that they had something other than the right amount of treatment. For the overall satisfaction domain, the five scores are averaged for a composite score that range from 0 = worst care through 50 = best care (Connor et al., 2005).

2.3.2.2.4 Validation of FEHC Instrument

The report of the validity of the FEHC refers to the validation of the Toolkit After-Death Bereaved Family Member Interview (Teno et al., 2001):

The purpose of this study was to examine the reliability and validity of the Toolkit After-Death Bereaved Family Member Interview to measure quality of care at the end of life from the perspective of family members. The survey included proposed problem scores (a count of the opportunity to improve the quality of care) and scales. Data were collected through a retrospective telephone survey. Family members were interviewed between 3 and 6 months after the death of the patient. The setting was an outpatient hospice service, a consortium of nursing homes, and a hospital in New England. One hundred fifty-six family members participated. The 8 proposed domains of care, as represented by problem

scores or scales, were based on a conceptual model of patient-focused, family-centered medical care.

The survey design was intended to emphasize face validity in order to provide actionable information to health care providers. A correlational and factor analysis was undertaken of the 8 proposed problem scores or scales. Cronbach's alpha scores varied from 0.58 to 0.87, with two problem scores (each of which had only 3 survey items) having a low alpha of 0.58. The mean item-to-total correlations for the other problem scores varied from 0.36 to 0.69, and the mean item-to-item correlations were between 0.32 and 0.70. The proposed problem scores or scales, with the exception of closure and advance care planning, demonstrated a moderate correlation (i.e., from 0.44 to 0.52) with the overall rating of satisfaction (as measured by a five-point, "excellent" to "poor" scale).

Family members of persons who died with hospice service reported fewer problems in each of the six domains of medical care, gave a higher rating of the quality of care, and reported higher self-efficacy in caring for their loved ones. These results indicated that 7 of the 8 proposed problem scores or scales demonstrated psychometric properties that warrant further testing. The domain of closure demonstrated a poor correlation with overall satisfaction and requires further work (Teno et al., 2001). Thus this domain was not explicitly included in the subsequent FEHC version developed.

2.3.2.2.5 Research studies using the FEHC Instrument

A selection of results of family evaluations of hospice care from the NHPCO data repository have been reported in published articles for the first two quarters of 2004 (Connor et al., 2005) and for the year 2005 in relation to timing of referral to hospice and quality of care (Teno et al., 2007) and in relation to hospice care for dementia patients (Mitchell et al., 2007).

Participation in the NHPCO is voluntary. Hospices are requested to contact bereaved relatives from one to three months after the patient's death to invite them to participate in a survey. The surveys are usually filled in by paper and pencil by the respondent. A telephone instrument is available for use with low literacy skills. Modes of administration testing have found that paper and pencil and telephone interview results are equivalent (Connor et al., 2005).

The results for the first two quarters of 2004 (from a total of 29,292 surveys) showed that on average respondents rated their overall satisfaction with care as 47.1 on a 50-point composite scale of five measures of satisfaction. Opportunities for improvement were identified for attending to family needs for support (18.2% of those surveyed reported at least one unmet need), attending to family needs for communication (10-29%), and coordination of care (22.1%). Surrogate reporting of unmet needs for pain, dyspnea, or emotional support ranged from 5.3% to 9.8%. The authors concluded that the FEHC is a useful tool for measuring hospice performance and identifies a number of opportunities for improvement (Connor et al., 2005).

In 2005, 106,514 surveys from 631 hospices were submitted to the NHPCO. Published findings have focused on the hospice length of stay and bereaved family member perceptions of the timing of hospice care. Results include that 11.4% of family members believed that they were referred “too late” to hospice. This varied from 0 to 28.1% among the participating hospice programs with 30 or more surveys. Only 16.2% of those with hospice lengths of stay of less than a month, reported they were referred “too late”. The bereaved family member perceptions of the quality of end-of-life care did not vary by length of stay for each of the FEHC domains. However, the perception of being referred “too late” was associated with more unmet needs, higher reported concerns, and lower satisfaction. The authors concluded that family members’ perception of the timing of hospice referral-not the length of stay-is associated with the quality of hospice care (Teno et al., 2007).

The 2005 FEHC data was used to describe hospice recipients over 65 years of age who died with dementia and to examine their families’ evaluation of hospice care. Decedents with cancer and chronic terminal conditions were examined for comparison purposes. A total of 77,123 surveys supplied by 796 hospices nationwide met the study’s eligibility criteria. Decedent diagnoses were: dementia, n=8,686 (11.3%); cancer, n=35,693 (46.3%); and other chronic diseases, n=32,744 (42.4%). Chronic diseases included heart and circulatory diseases, lung and breathing diseases, kidney diseases, liver diseases, strokes and frailty/decline due to old age (Mitchell et al., 2007).

In this study, the decedent was the unit of analysis. The researchers used frequencies to describe decedent characteristics, respondent characteristics, features of the hospice

program and care domains. Chi-squared tests were used to detect statistically significant differences in decedent, respondent and hospice program characteristics among the three groups. Mantel – Haenszel tests were used to examine if statistical differences among groups were present in the analyses examining the FEHC domains as outcome measures. The researchers reported that because of the large sample size and possibility for Type 1 errors, only proportions that differed by 5% between groups were considered clinically meaningful (Mitchell et al., 2007).

Results showed that decedents with dementia were more likely to be >85 years, female, and have length of stays >180 days. Evaluation of care in all FEHC domains did not significantly differ between groups. Approximately three-quarters of bereaved family members of decedents in all groups perceived the overall quality of care as excellent; however, opportunities to improve care were also identified. Similar proportions of respondents across groups reported at least one problem with co-ordination of care (17.5%), information from health care providers regarding the patients' overall condition (20.1%), information received about treatment of the patients' symptoms (12.2%), and the provision of emotional support to the family (29.8%). Unmet patient needs for the treatment of symptoms were less frequent, and also comparable in all decedent groups (pain, 5.5%; dyspnea, 4.7% and anxiety/sadness, 9.3%). The researchers concluded that the evaluation of hospice care for older patients is generally high, and does not vary with respect to terminal diagnoses. They believed that their findings were encouraging as they suggest that hospice providers can meet the challenges of end-of-life care in dementia as well as more common diagnosis among hospice recipients (Mitchell et al., 2007).

2.3.2.2.6 Assessment of suitability of FEHC for use in the evaluation of the HfH Programme

The suitability of the FEHC for use in the evaluation of HfH Programme is assessed next. The criteria for evaluation are the:

- extent to which the FEHC measures HfH Programme themes,
- psychometric properties of the FEHC
- extent to which the FEHC measures outcomes relevant to patients and families
- scope for further use of the FEHC in the evaluation of the HfH Programme
- FEHC foci of evaluation.

Extent to which the FEHC measures HfH Programme themes

The *FEHC Core Questions Version* (44 items) will firstly be assessed in terms of the extent to which it measures HfH Programme themes, followed by the *FEHC Complete Version* (61 items).

- The HfH theme of integrated care is assessed by 15 items across two domains, attending to family needs for support and co-ordination of care as well as by other stand-alone items. The sub-themes of integrated care assessed include symptom experience (n=1), symptom control (n=1), psycho-social supports (n=3), relative's of care patient (n=2), spiritual well-being (n=2), continuity of care (n=4) and quality of care (n=2). Six of the items refer to the care received by the patient and nine refer to the care received by the family members. The optional modules provide an additional question on overall satisfaction regarding the provision of emotional support to patients and the family.
- The HfH theme of communication is assessed by 9 items by the domain attending to family needs for information. The items are relevant to the FEHC sub-domains of medications and treatment for symptoms, family confidence in the provision of care to the dying person and patient's condition and what to expect. The HfH communication sub-themes assessed include information on patients' condition; treatment; supports and on what to expect. All these question items assess the care received by the relative. The optional modules provide an additional overall satisfaction question on how well the hospice team communicated with the patient and family members about the illness and about the likely outcomes of care. There are also two additional questions measuring the self-efficacy of the family in relation to knowing what to expect while the patient was dying and about knowing what to do at the time of death.
- The theme of patient autonomy is assessed by 3 items by the domain of provision of desired physical comfort and emotional support. The FEHC subdomains assessed include unmet needs for pain, dyspnoea and emotional support. The HfH patient autonomy sub-theme assessed is advance care planning - treatment preferences. The three items assess the care received by the patient. The optional modules provide additional questions on overall satisfaction with (a) end-of-life medical care that respected the patient's wishes (b) control of patient symptoms that was acceptable to him or her and (c) how well the hospice team made sure

the patient died on his or her own terms. There are also an additional two items measuring advance care planning, specifically if any member of the hospice team spoke to the patient or family about the patient's wishes for medical treatment as he/she is dying and if a doctor or other team member did anything with respect to end-of-life care that was inconsistent with the patient's previously stated wishes.

- The HfH theme of design and dignity is not assessed by the FEHC. Therefore important concerns such as personal dignity and the quality of the personal environment are not measured. However, additional modules also relate to the availability of hospital equipment and pharmacy. However these are not centrally relevant to a hospital environment.

Psychometric properties of the FEHC

The psychometric properties of the FEHC have been discussed with reference to the validation of the After Death Bereaved Family Member Interview. No studies were found that used the FEHC in a hospital setting.

Extent to which the FEHC measures outcomes relevant to patients and families

The FEHC appears to measure outcomes relevant to the care received by the patient and families in equal measure. One shortcoming is that no items measure, by proxy, the patients' views of communication and interpersonal style of hospital staff or of information received.

Scope for further use of the FEHC in the evaluation of the HfH Programme

The FEHC care was devised specifically for family members and does not present scope for use with health professionals.

FEHC foci of evaluation

The focus of evaluation of the FEHC is on the quality of care, with particular emphasis on the processes of care. However, items measuring the structure of care are not excluded. Connor et al (2005) state that the survey can be used to evaluate quality improvement efforts and to identify high performance areas, as well as areas that require improvements. As with other measurement instruments, it can be used to compare outcomes across settings. A strength of the FEHC is that, in many questions, it allows the respondent to define the standards of care required, for example if the care was the

right amount, more than was wanted, or less than was wanted. However, one shortcoming is that it is not explicitly linked to the HfH standards of care.

In summary, the FEHC is a useful tool to measure quality improvement initiatives such as the HfH intervention programme. The advantages of using it in the evaluation of the HfH programme is that it directly measures quality of care and it is applicable to the HfH themes of integrated care, communication and patient autonomy. One strong advantage is that it allows the respondent to define the ideal level of care received. These definitions of ideal care can form standards from which to interpret the research findings. The FEHC identifies good performance and areas for improvements through use of domain and problem scores. It is possible to administer the survey by post or telephone interview. The FEHC measures outcomes relevant to patients and families.

Disadvantages include that it does not directly measure the outcomes of care, for example the impact of care received on patients' quality of life or quality of death and dying.

However it does measure satisfaction with care as an outcome. It does not offer scope for further use with healthcare providers or permit a stakeholder analysis of the dying experience. It is not explicitly linked to the HfH standards of care.

2.3.2.3 VOICES Questionnaire

The Views of Informal Carers – Evaluation of Services (VOICES) is a shortened version of the Regional Study of Care for the Dying Interview Schedule (RSCD). It was developed based on the need for a short survey instrument that could be administered by post. VOICES assesses care received in the last year of life. The authors felt satisfied to recommend the instrument after the postal method of administration was proven to be in accordance with the preferences of bereaved relatives (Addington-Hall et al., 1998).

2.3.2.3.1 Development of the VOICES Questionnaire

The original interview schedule for the RSCD reflected important issues and ideas surrounding end-of-life care in the 1960s (Cartwright et al, 1973, cited in Addington-Hall et al., 2004). The initial VOICES questionnaire covered similar domains. However, as a result of advances in research, palliative care provision, and the changing political dimensions of health, the VOICES questionnaire has been revised to address contemporary issues surrounding death and dying (Addington-Hall et al., 2004).

The revised content and format of VOICES was formed following (1) literature reviews to identify appropriate ways of measuring service satisfaction and concepts of a good death, (2) interviews with professional stakeholders to identify issues they thought important to measure at the end-of-life and (3) focus groups with patients, bereaved relatives and professionals. Fourteen themes emerged from the analysis of this data: symptom management; choice and control; communication; information; dignity; quality of life; maintaining a normal life; carer support; access to services; preparation; co-ordination and continuity; questioning; relationships and safety and security. The most important themes were symptom management; preparation; dignity; co-ordination and continuity (Addington-Hall et al., 2004).

The revised VOICES questionnaire addressed these concerns. The new instrument was pre-tested with bereaved relatives using cognitive testing techniques. Respondents positively appraised the questionnaire and thought it was a valuable way of assessing services. Many reported completing the questionnaire was cathartic. Questions that had caused distress to respondents (e.g. questions about patient anxiety) were removed, restructured or reworded, as were questions that were misunderstood or seemed irrelevant to respondents (Addington-Hall et al., 2004).

2.3.2.3.2 Description of the VOICES Instrument

The VOICES questionnaire contains 48 questions, many sub-divided, generating over 160 items. It asks questions about the place of death, nursing care, hospital, hospice and GP care, and also on social services provision and symptom control, communication, global satisfaction for care received as well as free text questions at the end of each section. A final question asks respondents to make an overall assessment of the deceased's care, and invites respondents to comment in their own words, on the good and/or bad aspects of the care that was received (Costantini et al., 2005; Ingleton et al., 2004).

2.3.2.3.3 Analysis of VOICES Data

Questionnaire data is analysed using SPSS. Open ended questions can be subjected to content analysis to organize data into common themes and categories.

2.3.2.3.4 Research studies using the VOICES instrument

The VOICES instrument has been used in a number of studies in England and elsewhere to audit local services for people who die (Addington-Hall & McPherson, 2001).

Methodology and research findings from three studies (Carer Satisfaction with End of Life Care in Powys, Wales; Italian Study of Dying of Cancer; Regional Study of Dying of Cancer) that have used the VOICES or RSCD instrument are presented next.

- **Carer satisfaction with end of life care in Powys, Wales**

A self-complete, modified version of the VOICES instruments was used to examine levels of satisfaction with services provided for people in their last year of life in the rural county of Powys, Wales. The survey formed part of a larger 3-year evaluation of a general practitioner (GP) clinical facilitator scheme in the area (Ingleton et al., 2004).

Identifying and contacting potential respondents

The target population were relatives of those who died of cancer in Powys between April 1999 and June 2001. Death certificates formed the source of the sampling frame. The Office for National Health Statistics attempted to contact all those who had registered a death in the specified time period, at least six months after the death and invited them to receive a copy of the questionnaire. A covering letter from the researchers presented details of the study and a contact number for enquiries. Respondents were also invited to offer another name if they felt they were not the most relevant individual. A single reminder letter was sent to non-responders. Those who agreed to participate, were sent the questionnaire, with an accompanying letter giving information about the study, contact number and details of bereavement support agencies (Ingleton et al., 2004).

Of 805 relatives contacted (out of a possible 815), 407 agreed to receive the questionnaire. Of these 407, 301 (74% of those who agreed to receive the questionnaire, and 37% of those contacted) returned completed questionnaires. The authors indicated that this response rate was lower than similar studies using VOICES, perhaps because

they used an indirect method of contacting respondents. This was in order to comply with changes to data protection legislation (Ingleton et al., 2004).

The results of this study referred to a range of care settings and themes:

Place of care and of death

Most persons who died had spent time in hospital in the year before they died: 30% in a community hospital only, 32% in a district hospital only and 7% in a cancer centre only. Additionally, 24% had received care at both a community hospital, and a district general hospital or cancer centre. For 103 of 301 respondents, it was known that the deceased person wanted to die at home; only 44 (43%) did so (Ingleton et al., 2004).

Psycho-social supports

Twenty per cent of respondents had the opportunity to talk to someone from health and social services after their bereavement; a large majority (80%) found this helpful (Ingleton et al., 2004).

Symptom experience and control

Over 80% who died had experienced pain, and of these, 90% had treatment at home and 95% in hospital. The incidence of symptoms other than pain was generally higher at home than in the hospital. Nausea and vomiting were experienced by half of those in hospital and nearly two thirds of those at home, and loss of appetite was reported by nearly three quarters of those in hospital and over four-fifths of those at home. Nearly a quarter in hospital suffered from diarrhea and over two-fifths of those at home, whereas constipation was reported for a third of those in hospital and over half of those at home. Two-fifths of those in hospital suffered from breathlessness, with rather more at home suffering from this. Those who had problems sleeping formed nearly half of those in hospital and almost two-thirds of those at home. Symptoms were controlled better in hospital than at home, with the exception of diarrhea (Ingleton et al., 2004).

- **Italian Study of Dying of Cancer (ISDC)**

The VOICES survey instrument was also employed in the Italian Study of Dying of Cancer. This study was carried out to evaluate the experiences of Italian people dying

from cancer during their last three months of life in all care settings. It was approved by the Ethical Committee of the National Cancer Institute (Costantini et al., 2005).

Identifying potential participants

A two stage probability sample was employed. Firstly, to identify a stratified random sample (n=30) of Local Health Districts from a population of 197. The 30 LHD selected accounted for 15.3% of all annual adult cancer deaths in Italy. Secondly, to randomly select a fixed proportion of cancer deaths from each LHD, generating a total of 2000 death certificates. For each deceased patient, the non-professional care-giver (the closest and best informed person on the last three months of life of the patient) was identified. For those without a non-professional care-giver during their last three months of life, the health professional closest to the patient was identified. The caregiver was identified by contacting the patient's GP (Italian death certificates do not contain information about the caregiver). If this was unsuccessful, the clinical records of health services were examined (Costantini et al., 2005).

Procedure for contacting caregivers

A letter was sent to all identified caregivers informing them of the study aims and requesting their availability and consent to be interviewed. Between three and ten days later, a trained interviewer phoned potential respondents to assess if he/she had been effectively the closest and best-informed caregiver, and to arrange the details to conduct the interview. To avoid any possible manipulation from the interviewer, in case of refusal from the appropriate caregiver, the possibility to contact an alternative caregiver was not permitted (Costantini et al., 2005).

The VOICES interview

Non-professional caregivers were interviewed using a semi-structured questionnaire, derived from VOICES. The interview covered the last three months of life. The first four sections of the interview related to four different settings: home, nursing home, hospital and hospice. For each of these settings, respondents were asked about:

- Prevalence of pain and other symptoms, and the therapies received
- Quality of communication with professionals
- Type and quality of assistance received from physicians, nurses and other health professionals (or need for, if not received).

- Global satisfaction for care received

The fifth section asked questions about a number of domains independent of care settings:

- Loss of autonomy;
- Socio-economic problems experienced by the patient and their family;
- Psychological distress experienced by the patients and help received;
- Sharing of information with the patient and the family about the disease and its prognosis;
- Place and circumstances of death;
- Communication between family and health professionals after the patient's death, including the support received
- Global satisfaction for the care received

The last section was about the socio-economic status of the patient and other needs not covered by the interview. At the end of the interview, – a self-administered questionnaire (CES-D) measuring the frequency and severity of symptoms of depression – was administered to the caregiver. An interview with the caregiver was obtained for 1289 cancer deaths (64.5% of the overall sample; 67.8% of identified caregivers) (Costantini et al., 2005).

Response rate determinants

There were no differences in the response rate by age, gender and marital status of the patient. Caregivers of patients deceased in hospital were less likely to be interviewed compared to caregivers of patients deceased at home. Probability of caregiver participation increased with the increase in patients' educational level. The authors noted that the implication of this finding was that the survey results may have slightly overestimated the quality of care. This is due to the known association between lower social class and higher dissatisfaction with health services. There was a significant heterogeneity in the response rate among different caregivers. Compared to spouses, a higher probability of participation was observed for children, other family members and friends. The gender of the caregiver had no effect on the response rate. Timing of contact (the interval between patient's death and the first contact with the caregiver) was a significant determinant of response rate. Response rates decreased with an increasing

time after the patient's death (from about 80% four to six months after the patient's death to 50%-60% 10-12 months after patient's death) (Costantini et al., 2005).

The authors of this study compared their response rates to the only two other national mortality follow back surveys conducted since the seminal 1969 and 1987 UK surveys. These were the UK Regional Study of Care for the Dying (1990) and the US National Mortality Follow Back Surveys. Their comparisons showed that the proportion of the refusals was similar in Italy, the UK and the US (19.2, 23.4, and 21% respectively). The differences in the response rates were explained as due to different proportions of caregivers not identified or not located (13.1% in the ISODC, 5.9% in the RSCD and 18.8% in the US survey) (Costantini et al., 2005).

Reasons for refusal to participate

Psychological suffering was present in 99% of refusals examined for this dimension (48%). Conversely, a poor quality of care was reported by 63% of the refusals examined for this dimension (23%) (Costantini et al., 2005).

Impact of participating in the research on respondents

The impact of post-bereavement interviews was analysed in a small sample of bereaved family members interviewed four to five months after patients' death. Over 80% experienced mild or no distress, and none considered the interview unhelpful. Only 5.4% reported their experience of completing the survey as very or extremely distressing (Costantini et al., 2005).

ISDC Research Results

The results and key findings of the ISDC have been widely published. Key results related to the following themes:

Communication

Over one third (37%) of people who died of cancer had received information about diagnosis and 13% about poor prognosis. Higher proportions, although non-informed, knew the diagnosis (29%) and the poor prognosis (50%). The probability to be informed was higher for those who had lived in the North of Italy, who were young, highly

educated with longer survival, and who had breast or head and neck tumours (Costantini et al., 2006).

Accessibility of palliative care services for cancer patients

Access to palliative care services was strongly associated with socio demographic characteristics of the patients and their caregivers. For example, only 14% of Italian cancer patients cared for at home and 20% of those admitted to hospital received palliative care support. The key determinants were an extended interval between diagnosis and death and the caregiver's high educational level for patients at home; the low patient's age and the caregiver's high education level for patients in hospital (Beccaro et al., 2007).

Financial impact of dying of cancer on the family and caregiver

A specific section of the VOICES questionnaire asked questions about the financial burden of the disease on social activities and employment of the caregiver and family. Results demonstrated that although Italian families are responsible for a small percentage of the overall costs of patient care, the effect of cancer on savings and daily life can be considerable. Strong geographic and gender differences were evidenced. Particular results indicated that of over two thirds (68%) of families who had to pay for some of their care, 37% had to pay for drugs, 36% for nursing and assistance and 22% for physicians. To pay for the costs of patient care, approximately one quarter of families used all or most of their savings. The length of time the patient was completely dependent strongly determined the effect caregiving had on their regular employment and on the family's financial situation (Giorgi Rossi et al., 2007).

Actual and preferred place of death of cancer patients

Place of death was mainly either home (57.9%) or hospital (34.6%) for Italian cancer patients. Home was the preferred place of death for 93.5% of patients who expressed that preference. Over two thirds (67.1%) died in the place where they preferred to die. The authors concluded that policy makers should encourage health services to focus on ways of meeting individual preferences on place of death (Beccaro et al., 2006).

- **Regional Study of Care for the Dying (RSCD)**

The RSCD interview protocol was utilized in the 1990 RSCD. Its methodology and findings are reviewed next. These are beneficial as they highlight considerations necessary for the design of the evaluation of the HfH Programme and for the analysis of bereaved relatives' survey data.

Aims of RSCD

The aims of the RSCD was to provide district health authorities in the UK with an audit of local services for the dying and to examine experiences of people dying from cancer and other illnesses, effectiveness of hospice care, and needs of, and appropriate service provision for patients. The sites of care examined included inpatient and outpatient hospital care, hospice care and community services across twenty district health authorities (Addington-Hall & McCarthy, 1995).

Identifying potential participants

All district health authorities in England were invited to take part in the survey. Within each district, the sample was drawn from death certificates of district residents dying in the last four months of 1990. A target of 200 completed interviews for each area was set (Addington-Hall & McCarthy, 1995).

Procedure for contacting caregivers

A letter was sent to the usual address of the deceased (as identified on the death certificate), 10 months after the death, informing relatives about the study and that they would shortly be contacted by an interviewer. This allowed those who did not want to participate to contact the researchers before the interviewer called (Addington-Hall & McCarthy, 1995).

RSCD interview schedule

One to one interviews were conducted with people who knew about the last year of life of a random sample of persons (n=3, 696) who died in 1990, across the twenty health districts. The research instrument (the RSCD interview schedule) used was an adapted version of the Cartwright and Seale interview schedule. Those who participated in the study were mainly spouses or close relatives, but also included other relatives,

friends/neighbours and officials (Addington-Hall & McCarthy, 1995). This composition of respondents differed to the ISDC.

RSCD Research Findings

The findings of the RSCD have been disseminated widely in journal publications. Published findings have related to different cohorts of respondents including relatives of patients who died from cancer, non-cancer diseases, heart disease, stroke and dementia (Addington-Hall et al., 1998; Addington-Hall et al., 1995; McCarthy et al., 1997a; McCarthy et al., 1997b). Another publication is dedicated to the satisfaction of informal caregivers (Fakhoury et al., 1996).

A selection of key findings from these publications is presented next.

Heart disease patients

Of the 3, 696 interviews completed, 675 related to patients who had died of heart disease (McCarthy et al., 1997b). The findings for this specific group, not including those who had died suddenly (n=75) are detailed below. The findings are from respondents who were family or friends.

- *Information about illness:*

Just under half (47%) of the respondents felt they had not been able to get all the information regarding the deceased's illness that they had wanted and when they had wanted. Hospital doctors were reported as being more informative than GPs, however respondents have found GPs more supportive (McCarthy et al., 1997b).

- *Knowledge of prognosis:*

Half the patients were said to have known or probably known, that they were likely to die. The majority (82%) of these worked this out for themselves rather than being told by a health professional. Sixty-three per cent of respondents reported they had known (37%) or had half known (26%) that the deceased was likely to die (McCarthy et al., 1997b).

- *Support in dying:*

More than one-third of patients (39%) died without an informal carer present. This figure represented 32% of patients under 55 and 40% of those over 75. Overall 30% of respondents were present at the death. Two thirds of those not present at the death said they would have liked to have been (McCarthy et al., 1997b).

- *Place of death:*

Over half (54%) died in hospital, 30% in their own home, 11% in a nursing or residential home and 4% in other places. Patients aged under 75 were less likely to die in a hospital or another institution, and more likely to die at home, than patients 75 plus. Respondents felt there was not enough choice regarding the place of death. This finding referred to both family/carers (43%) and patient (40%) choice (McCarthy et al., 1997b).

- *Time to die:*

Respondents said that a quarter of patients had wanted to die earlier: this desire was associated with older age and the number and severity of symptoms (McCarthy et al., 1997b).

The conclusions drawn from these findings were that health professionals infrequently discussed with heart disease patients their likelihood of dying. The finding about wishing to die sooner was viewed as a possible reflection of poor symptom control. Authors concluded that clinicians caring for heart disease patients ought to have an understanding of communication about dying similar to cancer physicians and should discuss preferences for place of care more actively (McCarthy et al., 1997b).

Stroke patients

Published findings about stroke patients have focused on symptom control and satisfaction with hospital care for example. Subjects were 237 persons who died from stroke in 1990. Of the 237 stroke deaths, two thirds died in hospital. For 65% of the sample, the time between the patients' first stroke and their death was ascertained. The majority of patients survived for a relatively short time after their first stroke (One patient in ten died within 24 hours of their first stroke, two fifths survived for longer than one day but less than one month, 15% for between one and six months, and the remaining third for longer than six months) (Addington-Hall et al., 1995). Results focusing on

symptom experience, symptom control, communication and hospital care are presented next.

- *Symptom experience:*

Authors examined the presence, duration and severity of symptoms in the last year of life. More than half the patients were reported to have experienced pain (65%), mental confusion (51%), low mood (57%), and urinary incontinence (56%) in the last year of life. Breathlessness, insomnia, loss of appetite, constipation and loss of bowel control were reported to have been experienced by at least one third. Many were reported to have had these symptoms for at least 6 months.

The symptoms reported to have been common in the last week of life were urinary incontinence (51%), pain (42%), mental confusion (41%), low mood (33%), and fecal incontinence (31%). These symptoms were less common in the last week of life than in the last year (Addington-Hall et al., 1995).

- *Symptom Control:*

Pain control was inadequate: 51% of those treated for pain by hospital doctors and 45% of those treated by general practitioners were reported to have received treatment that relieved pain, partially, if at all. Control of breathlessness, nausea/vomiting, and constipation was viewed as more effective (67%, 60% and 84% of respondents reporting that the symptom was controlled a lot/some respectively). The authors concluded that the results may under-estimate the misery caused by poorly controlled symptoms. This was due to the difficulties of making judgements about symptoms experienced by patients whose ability to communicate and/or level of consciousness may have been affected by stroke (Addington-Hall et al., 1995).

- *Use of and Satisfaction with Hospital Inpatient Care*

Of patients who did not die immediately from stroke, over three quarters (79%) had been admitted to hospital in their last year of life. Nine per cent had spent fewer than 3 months in hospital, 19% three nights to one week, 31% one week to one month, 27% one to three months and 13% had been in hospital for more than 3 months. Overall care from nurses was rated higher than that from doctors: 29% rated hospital

doctors' care as excellent, whereas 46% rated hospital nurses this high. Fewer than one in 10 respondents felt that the doctors' or nurses' care had been poor. More than one third (37%) felt that doctors had been too rushed, and one quarter thought that the deceased had too little choice about treatment. Hospital facilities were criticized - one quarter felt that the deceased had had insufficient privacy and one fifth reported that the deceased's room had not been peaceful at all or quiet. Nearly one fifth of respondents felt that they had been treated with indifference or had even had a hostile reception when visiting the deceased (Addington-Hall et al., 1995).

The authors concluded that the results showed that many patients who die of stroke do not receive optimal symptom control and identified shortcomings in hospital care. They concluded that the results show the significance of providing care for stroke patients and their families that encompasses their physical, emotional, and social needs and aims to improve the quality of life remaining (Addington-Hall et al., 1995).

Satisfaction of Informal Caregivers

The RSCD authors also examined the relationship between the satisfaction of informal carers with the care delivered to dying people in the last year of life and patient and carer characteristics. A secondary analysis was conducted on 1, 858 informal carers who were relatives or friends/neighbours of people who died from cancer. Over one quarter (n=504; 27.4%) of 1, 836 informal carers were highly satisfied with the health and social services to 72.6% (1,332) who were less satisfied with these services. The analysis showed that informal carers' overall satisfaction with health services is predicted by carer and patient attributes. The carers experience of caring variables were stronger predictors than sociodemographic and clinical variables (Fakhoury et al., 1996). Key results were:

(a) Patient attributes

- Sex, age, ethnic origin, religious affiliation, whether the decedent had living siblings, the site of the malignant neoplasm, the duration of pain, gastro-intestinal symptoms and incontinence were not significantly associated with informal carers' satisfaction (Fakhoury et al., 1996).
- Factors such as the patient's duration of functional limitation, confusion and psychological symptoms were found to predict satisfaction. Informal carers who

perceived that the deceased had had a high degree of functional limitation and had experienced confusion, psychological symptoms and respiratory symptoms for a short rather than longer period of time were significantly more likely than their counterparts to report high satisfaction (Fakhoury et al., 1996).

(b) Carer attributes

- Sex, housing tenure, religious affiliation and adjustment to bereavement to bereavement had no significant association with satisfaction. However, informal carers who were aged 65 years or over, those who were spouses of the deceased, those who had lived with the deceased, those who were living alone after the deceased's death, those who were unmarried at the time of the interview and those who had a strong religious faith were significantly more likely than others to be highly satisfied (Fakhoury et al., 1996).
- Those who rated their post-bereavement health as excellent or good and those who reported having had no bereavement-related psychological problems were significantly more highly satisfied than those who rated their health as fair or poor and those who reported having had at least one psychological problem as a result of the bereavement (Fakhoury et al., 1996).

The authors concluded that developing a profile of satisfied informal carers is important in order to target non-satisfied informal carers and improve their level of acceptability of the service. They also concluded that this is important for successful coordination of care and a better relationship between formal and informal carers (Fakhoury et al., 1996).

The relationship between symptoms, dependency levels and age.

Another secondary analysis examined variations by age in symptoms and dependency levels experienced by people in the last year of life for cancer and non-cancer patients (Addington-Hall et al., 1998).

Key results showed:

- In cancer patients, the mean number of symptoms reported to have been experienced in the last year of life decreased with age, while the number of symptoms reported to have lasted more than six months increased.

- In both cancer and non cancer patients the proportion of symptoms reported to have been “very distressing” decreased with age. The authors suggested that elderly populations may under-report their symptom distress because of more stoical attitude and communication difficulties arising from increased prevalence of cognitive failure in this group. The authors concluded that younger cancer patients are more likely than older cancer patients to need help with relieving distressing symptoms. However that older people should not be excluded from specialist services based on age.
- In non-cancer patients the average number of self-care tasks the deceased needed help with increased substantially with age; in cancer patients the mean level was higher and there was no age gradient. The authors suggested that this finding showed the need for a range of health services to be made accessible for cancer patients of all ages.
- Other research has also shown that people dying from cancer tended to have more distressing symptoms which were of relatively short duration while people who died from causes other than cancer had less distressing and long lasting symptoms (Seale and Cartwright, 1994 cited in (Addington-Hall, Altmann et al., 1998).

The authors concluded that this type of analysis is important in order to identify information about age-related inequalities in care for the dying.

2.3.2.3.5 Assessment of suitability of the VOICES instrument for evaluating the HfH Programme

Copies of the VOICES questionnaire were not available for thematic analysis at the time of the literature review. However, assessment of studies that have used the instrument have made possible a number of conclusions about its suitability for use in the evaluation of the HfH Programme:

- The VOICES instrument addresses the HfH themes of integrated care and communication, however does not sufficiently address the HfH themes of patient autonomy and design and dignity.
- The VOICES instrument is not for use in a single setting such as a hospital, but rather the four main care settings – home, nursing, home, hospital and hospice. This would suggest that the instrument isn’t suitable for evaluating an intervention in a hospital.

- However, the reports of its methodology and research findings are useful in devising research designs and data analysis strategies.

In summary the relative advantages and disadvantages of using the QODD, FEHC and VOICES instruments to evaluate the HfH Programme from the point of view of bereaved relatives is addressed in the summary and conclusion to the literature review. Particular methodological and ethical issues in conducting bereavement follow back surveys are assessed next.

2.3.3 Methodological and ethical issues in conducting bereavement follow back surveys

This section reviews the literature on methodological and ethical issues in conducting bereavement follow back surveys. Retrospective research in end-of-life care is said to be valuable because it avoids reliance on the complex task of prospectively identifying the terminally ill, avoids burdening very sick participants, minimizes missing data because of poor functional status, creates a clear time frame for the purpose of comparing settings of care, and is a cost effective method (Teno, 2005). However, the conduct of bereavement follow back surveys is not without challenges (Fowler et al., 1999; Teno, 2005). The most pertinent challenges relevant to the evaluation of the HfH Programme are highlighted next. These include the:

- Acceptability of using postal questionnaires to obtain the views of bereaved relatives
- Validity of using bereaved relatives as proxies
- Time interval, after the patient's death, to contact relatives about participating in research
- Procedures for identifying potential respondents
- Procedures for contacting potential respondents
- Procedures for identifying the most informed respondents
- Appropriate time frame from which to assess end-of-life care
- Impact of participating in the research on respondents
- Procedures for avoiding and managing distress
- Strategies to maximize response rates
- Analysing and interpreting bereaved relatives data

2.3.3.1 Acceptability of using postal questionnaires to obtain the views of bereaved relatives

Postal questionnaires have been found to be acceptable methods of conducting bereavement follow back surveys in a number of studies (Addington-Hall et al., 1998; Jacoby et al., 1999; Lecouturier et al., 1999). Addington-Hall et al, (1998) for example, conducted a randomised controlled trial of postal versus interviewer administration of a questionnaire measuring satisfaction with, and use of, services received in a year before death. The response rate did not differ significantly between postal (52%) and interview groups (56%). Postal questionnaires did have significantly more missing data and responses between the groups differed on 11 of 158 questions. The study learning outcomes identified strategies to minimize these effects including careful piloting of questionnaires.

This study considered that bereaved relatives might like to complete sensitive questions themselves rather than to be asked face to face by an interviewer. However, they also considered that bereaved relatives may prefer a face to face interview where they can discuss their concerns and talk about the deceased. They concluded that postal surveys need to be cognizant of these issues. They highlighted the importance of contacting bereaved relatives in a sensitive manner, of explicitly stating participation as voluntary and of making efforts to avoid and minimize any distress caused by virtue of being contacted in relation to the research. For example, although it is not standard practice in postal questionnaire surveys to precede the questionnaire with a letter, this procedure should be adopted to minimize the likelihood of causing distress to the bereaved families by receiving a questionnaire without having consented to receiving it (Addington-Hall et al., 1998).

An advantage of postal questionnaires is that family members may contribute more to the completion of the postal questionnaires and respondents may feel more likely to report socially undesirable feelings such as depression or anger. Postal surveys are also cheaper and it is possible to have a larger sample size for a given cost, hence improving the variance of estimates (Addington-Hall et al, 1998).

Therefore it can be concluded that use of postal surveys to evaluate the HfH Programme is an acceptable approach. This is due to this methods largely neutral effect on responses

and response rate, its cost effectiveness and its amenability to replication among a large sample of hospitals and bereaved relatives.

2.3.3.2 Validity of using bereaved relatives as proxies

A challenge of doing retrospective surveys is evaluating the validity of respondents' answers. A number of reviews have addressed this issue (Addington-Hall & McPherson, 2001; Fowler et al., 1999; Higginson et al., 1994; McPherson & Addington-Hall, 2003; Sprangers & Aaronson, 1992; Teno, 2005). In particular, they have addressed the report of symptoms and the effect of grief on respondent recall.

These reviews highlighted concerns about the validity of a proxy report for subjective states (Teno, 2005). Family members are more likely to over report pain severity in comparison to patients, whereas physicians have been found to underestimate the pain intensity of their patients (Fowler et al., 1999). In relation to family members, it has been suggested that accounts of pain may reflect more the respondent's distress at watching the patient in pain than the patient's subjective experience of pain (Addington-Hall et al, 1998). For objective observations, family members are able to report with sufficient accuracy (Tang 2002, cited in Teno, 2005).

Furthermore, Hinton (1996) examined patients' prospective and relatives' retrospective accounts of end-of-life care for terminal illness. Proxies showed poor agreement for symptoms when their responses after death were compared with patients' responses before death. Agreement about pain, depression, and anorexia was poor, whereas agreement about dyspnea, nausea and vomiting, anxiety and malaise was moderate or substantial. A single-item overall measure of satisfaction had moderate agreement (Hinton 1996 cited in Teno 2005).

Another issue concerning validity of proxy reports is the extent to which grief affects a proxy recall or perceptions of the quality of care (Fowler et al., 1999). Research has suggested that families change their assessments throughout the bereavement process. Hinton (cited in Teno, 2005) found that proxies demonstrated improved concordance with a terminally ill patient prior to death as compared with concordance of patient prior to death and a proxy report after death. Teno (2005) hypothesized that family members with anxiety or depression are more likely to focus on the negative aspects of the dying

persons' medical care. McPherson and Addington-Hall (2004) found that pain and depression ratings were less severe and less frequent with the passage of time.

It can be concluded that these issues are natural limitations of conducting retrospective research but need to be considered in formulating research designs and in interpreting research findings.

2.3.3.3 Time interval, after the patient's death, to contact relatives about participating in research

Another challenge for conducting retrospective end-of-life care surveys is determining the time interval, after the patient's death, to contact bereaved relatives about participating in research. This is both an ethical and methodological concern. *Ethical* in terms of determining the appropriate time frame in order to avoid causing distress to the relative and *methodological* in terms of determining the appropriate timeframe in order to get maximum responses and accurate recall of events.

According to Teno (2005) four studies have examined the impact of timing of the interview in relation to the perception of quality of end-of-care. She reported that of these, Lynn et al (1997) found similar responses between those who completed an interview early during bereavement as compared to those who were interviewed at a later time point. Cartwright et al (1973) found factual information to be similar at both time periods (3 and 9 months) and no significant differences for symptoms, help or care received. There were more refusals at 3 months and an increase in difficulty of locating respondents at 9 months. The changes observed were for reports of symptom frequency and severity to lessen during bereavement. No study has yet examined whether proxies assessments of quality of care changes during a period of bereavement (Teno, 2005).

The review of retrospective research on end-of-life care has not revealed a standardized time period after the death in which bereaved relatives have been contacted about participating in research. Table 7 summarizes the approach taken in a number of key national and international studies. It also considers the time period of care assessed, methods of administration and response rates.

Table 7: Summary of methodological approaches used in retrospective surveys

Study Title:	Time between Bereavement and research contact	Time period of care assessed	Method of Administration	Response Rate*
<i>International Studies</i>				
1. QODD Studies Seattle Study (2003)	3 months (mean)	Last few days or last month of life	Face to Face interview	33% (120 of 309 patients and family members)
Montana Study (1997)	1 - 3 years	Last few days or last month of life	Face to Face interview	36% (252 of 692)
2. ICU QODD Studies 4 Site ICU Study	4 months – 1 year	Last several days of life	Face to Face interview	38% (41 of 108)
2 Site ICU Study (2000)	1 month	Last several days of life	Telephone	55% (50 of 91)
3. Family Evaluation of Hospice Care Data Repository (2005)	1-3 months	Time period under care of hospice	Postal	45% (106, 514 of 236, 698)
4. Italian Study of Dying of Cancer (2005)	4-8 months (59%) 9-10 months (35%) 11-12 months (6%)	Last three months of life	Face to Face interview	64.5% (1289 of 1998)
5. Regional Study of Care for the Dying (1990)	9 to 12 months (10 months median)	Last year of life	Face to Face interview	69% (3696 of 5375)
6. End-of-Life Care in Powys, Wales (2001)	At least six months	Last year of life	Postal	74% (301 of 407) of those who agreed to receive the survey 37% (301 of 805) of those contacted
7. Lay carers' satisfaction with community palliative care (1999)	3 months	Last year of life	Postal	44% (156 of 355)
<i>Irish Based Studies</i>				
8. Bereavement Care in Acute Hospitals: an evaluation of the Beaumont Hospital Bereavement Care Service (2007)	At least one year	Bereavement support at time of dying and after the death	Postal survey	40% (335 of 839)
9. Care for the Dying Project: St Vincent's University Hospital (2007)	At least 12 months	Last days of life	Postal survey	54% (189 of 348)
10. Care for the Dying – experiences and challenges: St. James's Hospital (1999)	7 to 18 months	Last year of Life	Face to Face interview	57% (155 of 293)

*Response rates were calculated by those eligible and contactable or as otherwise stated

2.3.3.4 Procedures for identifying potential respondents

In all of the studies examined, next of kin information was either identified from death certificates or patients' medical records. Of the three Irish based studies (Table 7), all identified next of kin information from the patient's file. Each study, with the exception of one conducted on an audit basis and assessing bereavement support rather than end-of-life care (Walsh et al., 2007), had applied for and received ethical approval. Specified time periods over which to generate a sample of deaths were chosen. Depending on the aims of the study, appropriate inclusion and exclusion criteria were applied. For example, the Care of the Dying Project in St. Vincent's University Hospital excluded relatives who had died in the Intensive Care Unit and the Accident and Emergency Department as it was considered that death, dying and bereavement in these settings warranted separate inquiry. Sudden and unexpected deaths were also excluded because the focus of the study was on patient and family care in the hours and days leading up to the death (St Vincent's Palliative Care Team, 2007). The St James's Hospital Study also excluded sudden deaths (Keegan et al., 1999). The Beaumont Hospital study included all deaths because its focus was specifically on bereavement care (Walsh et al., 2007).

2.3.3.5 Procedures for contacting potential respondents

Typically studies have firstly contacted respondents by letter. This is to introduce a study and inform respondents that they will be contacted by a researcher to arrange an interview or that they will be given a questionnaire. They are also informed that participation is voluntary and are usually requested to contact the researchers, or fill in a refusal slip, if they do not want to be contacted further in relation to the research. Prior to contacting patients, some studies have contacted the patients' GPs in order to ascertain the relatives' suitability in relation to being contacted about the research. The rationale is that GPs would have a likelihood of knowing if contact about participating in end-of-life care research would upset the relative. For example, potential respondents may have had a recent bereavement or may have an illness themselves. This approach was taken in a minority of the studies outlined in Table 7.

2.3.3.6 Procedures for identifying the most informed respondents

A challenge of doing retrospective surveys is locating people who can provide information about the dying experience. The people who know most about the last days of life may not be the same ones who know about the preceding weeks or months (Fowler et al., 1999). Thus, Mularski and Curtis et al (2004) cited in Teno (2005) reported only moderate agreement among 94 family respondents for 38 decedents.

To ensure valid responses and that the person who knows most about the care received fills in the questionnaire; researchers have asked the respondent to consider if they are the most the most appropriate person to fill in the questionnaire and if not, to pass the questionnaire on to the most appropriate person. This has been the case in many surveys of bereaved relatives using postal methodologies (Addington-Hall et al, 1998).

2.3.3.7 Appropriate time frame from which to assess end-of-life care

The appropriate time frame from which to assess end-of-life care will change depending on the aims and location of a study. The time frames of studies examined in this review ranged from the last few days of life to the last year of life (see Table 7). Those who examined the last few days or last month of life were usually studies that focused on one care setting, such as a hospital or ICU department. Studies that examined the last year or three months of life, focused on a range of care settings including the patient's home, hospices, nursing homes and hospitals. Some studies asked respondents to assess care for the length of time patients were under the care of a particular care provider, for example a hospice. Given that the HfH Programme is concerned with care in hospitals, the latter would be an appropriate approach to take. Respondents could be asked to give details about the number of admissions and length of stay over a specified time frame. Length of stay would have particular relevance for patients' last admission to hospital.

2.3.3.8 Procedures for avoiding and managing distress

A potential discomfort or distress to participants is being contacted in relation to research on dying, death and bereavement. A structured interview based Irish study found 41% of relatives experienced significant psychological distress at the time of interview (median 16 months) as assessed by the General Health Questionnaire (Keegan et al., 1999). Three quarters still missed the person 'a great deal' and over half were less able to look forward to things in the same way as they did before the patient died. Research by Seamark and

Gilbert et al (2000) detailed that 80% of those interviewed showed only mild or no distress and did not comment that the interview was unhelpful.

Procedures for avoiding and managing distress in evaluating the HfH Programme from the point of view of bereaved relatives are therefore adhering to the appropriate methodological approaches outlined in the study and making methodological and ethical decisions based on the evidence collected. It is also best practice for support agencies' contact telephone numbers to be presented to respondents in case of distress associated with the research (Walsh et al., 2007). This approach applies for postal surveys, which is the planned approach for this study. Guidelines for avoiding and minimizing distress in the case of telephone and face to face interviews are available.

2.3.3.9 Strategies to maximise response rates

The review of the literature identified some strategies to maximize response rates in addition to good standard scientific practices. These include:

- Considering the likely effect of introducing the study by letter from the hospital, voluntary organization or academic department.
- Careful piloting to ensure use of simple language and comprehension
- Contacting the most informed respondent
- Offering an incentive to reply, such as a donation to a preferred charity for each questionnaire returned
- Use of reminder letters

(Addington-Hall et al., 1998; Walsh et al., 2007)

2.3.3.10 Analyzing and interpreting bereaved relatives data

The literature highlighted some important issues for analyzing and interpreting bereaved relatives data. It was reported that in surveys where the study location is the hospital site, data collection protocols and data interpretation may be confounded by the heterogeneity of patients with terminal disease, the high likelihood that people are in very bad conditions at the time they are hospitalized and the fact that some people who are admitted to hospital will end up dying somewhere else. A critical research step is therefore to sort patients into meaningful groups, for which the issues or standards for quality of care and quality of the treatment process would be similar (Fowler et al., 1999). This issue will be particularly important in the analysis and presentation of the data.

2.4 Summary and Conclusion

This literature review and its significance for planning the evaluation of the HfH Programme from the point of view of bereaved relatives are summarized next.

A conceptual framework detailing all the relevant domains that are appropriate for describing and evaluating end-of-life care was presented. This demonstrated all the variables that need to be taken into account when evaluating end-of-life care, including patient factors, the structure and process of care and the outcomes of care. It was reported that it is necessary to have an evaluation focus such as quality of care, quality of life or quality of death and dying. These framework components can act as quality of care indicators when the research findings can be interpreted in light of patient/and family preferences and standards for end-of-life care. The framework presented was found to be in accordance with patient and family preferences about what is important to measure about end-of-life care.

The review examined three instruments - QODD, FEHC and VOICES - that measure particular framework components or aspects of end-of-life care experiences. These were assessed in terms of the extent to which they measured HfH Programme themes, their psychometric properties, usage in different settings and samples, and methods of administration. Findings from studies using the research instruments were also presented.

Proposed advantages of using the QODD to evaluate the impact of the HfH Programme from the point of view of bereaved relatives were that it is applicable to the HfH theme of integrated care, it has sound psychometric properties and scope for use in a stakeholder analysis of the dying experience. Its formulation of a quality of death and dying score was proposed a useful way to monitor change in outcomes. Proposed disadvantages were its lack of measurement of the HfH communication theme and sparse measurement of the HfH themes of patient autonomy and dignity and design. It was also found not to measure the care received by families and has not been previously administered by post.

The FEHC was proposed as a useful tool to evaluate the HfH Programme as it identifies good performance and areas for improvements through use of domain and problem scores. Proposed advantages of its use were that it directly measures quality of care and is applicable to the HfH themes of integrated care, communication and patient autonomy.

Another advantage was that it allows the respondent to define the ideal level of care received and thereby contextualizes the research findings. The survey can be administered by post and measures outcomes relevant to patients and families. Disadvantages include that it does not directly measure the outcomes of care, for example the impact of care received on aspects of a patient's quality of life or quality of death and dying. However it does measure satisfaction with care as an outcome. It does not offer scope for further use with healthcare providers or permit a stakeholder analysis of the dying experience. It is not explicitly linked to the HfH standards of care.

The review of the VOICES instrument was viewed as most beneficial for the reports of its methodology, postal administration and research findings. The instrument itself, based on the evidence available, was not deemed suitable for use in evaluating the HfH Programme from the point of view of bereaved relatives because it has been designed for use in the four care settings (home, nursing home, hospital, hospice). It also did not comprehensively address HfH Programme themes.

The review of methodological and ethical issues in conducting bereavement follow-back surveys showed that postal questionnaires are an acceptable way to obtain the views of bereaved relatives. The validity of using bereaved relatives as proxies has been established although there are some limitations. For example, over-reporting for subjective states and the influence of grief, depression and anxiety on responses. The latter were said to decrease with the passage of time. There was no evidence of a standardized time interval after the death from which to contact bereaved relatives about participating in research. This ranged from 1 to 18 months. Evidenced based procedures for identifying and contacting bereaved relatives were identified in addition to guidance on the appropriate time frame from which to assess end-of-life care. The significance of procedures for avoiding and managing distress, strategies for maximizing response rates and analyzing and interpreting data were also presented.

Therefore, in sum, the value of the literature review is in providing evidenced based choices about how to approach the evaluation of the HfH Programme from the point of view of bereaved relatives. The key choice centres around using the QODD or the FEHC. This inevitably is a choice between evaluating the quality of death and dying versus the quality of the structure and processes of care. Each approach has pros and

cons and neither instrument addresses the HfH themes in their entirety. While the FEHC is more advantageous in this regard, questions about the design and dignity theme are required to supplement either questionnaire. Both questionnaires allow the formulation of outcome scores which is useful for monitoring change on a time series basis.

Considering all aspects of the evidence, it is the view of the authors that the FEHC may be most advantageous for use. It covers most of the HfH themes and allows respondents to define the ideal standard of care from the point of view of the patient and themselves as family members. It thereby adequately considers patient and family autonomy in evaluating care received. Since the FEHC is essentially a continuous quality improvement tool, findings will always identify areas for improvement. When used on a time series basis however, benchmarked findings will indicate change in care practices and in care received according to patient and family preferences. However, the disadvantage is that the FEHC will not identify in a detailed manner the change in outcomes (i.e. the impact of care on aspects of the quality of death and dying or quality of life) experienced by patients and families.

Finally, any planned survey to evaluate the impact of the HfH Programme will do so mainly through the lens of one particular framework component. The survey can form one of a number of measures of programme progress in conjunction with other planned evaluations perhaps from the point of view of patients, hospital staff members or from audit of hospital information systems. The results of the survey will need to be considered in combination with these in order for the survey to have maximum evaluative power. Evidence based guidance on evaluating end-of-life care has conceptualized care as a complex multi-dimensional issue requiring a range of data collection methods in combination or in sequence (Addington-Hall et al., 1998). Thus while the results from a bereaved relatives survey itself will be valuable for understanding their perspective and experience of end-of-life care, the programme evaluation requirement of the survey will require combining survey results with other data sets for maximum insight and understanding.

3 Methodology

3.1 Introduction

The overall aim of this study was to assess the quality of end-of-life care in acute and community hospitals from the perspectives of bereaved relatives. Sub-objectives were to describe a census of deaths across study sites; to field test a survey instrument aimed evaluating the impact of the Hospice friendly Hospitals (HfH) Programme; to collect data about HfH Programme themes; and to establish if there were any differences in the pattern of results between acute and community hospitals. This chapter outlines the methodology; including the research design, sampling frame collation, procedure for contacting potential participants, data analysis, ethical considerations and questionnaire development.

3.2 Research Design

A retrospective research design was employed to operationalise the study aims.

3.2.1 Study Sampling Frame

A study sampling frame of deceased patient and contact person details was compiled to describe a census of deaths and to generate a sample for the end-of-life care survey. Hospital data collectors (a registered nurse and a clerical officer) compiled the study sampling frame in each site. Means of data collection were through accessing the patient's file and through in-hospital reporting systems.

The sampling frame detailed the number and type of deaths that occurred over a one year period in the acute hospitals and over a two year period in the community hospitals (Table 8). Other descriptive data, without any identifying information from individuals, were also included. These included details about patient demographic characteristics, presenting complaint, cause of death, length of last hospital stay and contact person details, including relationship between contact person and patient.

Of the 941 deaths in the sampling frame, 78% were acute hospital deaths and 22% were community hospital deaths. Of the 737 acute hospital deaths, 50% were patients who had

died in hospital after at least 24 hours length of stay, 41% were patients who were brought in dead to hospital and 9% were patients who had died in Accident and Emergency (AE) within twenty-four hours of arriving to hospital. Of the 204 community hospital deaths, all were patients who had died in hospital after at least 24 hours length of stay.

Table 8: Description of the sampling frame by type of death

	All types	HBD > 24hrs		AE < 24hrs		BID	
	N	N	%	N	%	N	%
All Sites	941	569	60	70	7	302	32
Acute Hosp A	316	137	43	15	5	164	52
Acute Hosp B	421	228*	54	55	13	138	33
Community Hosp A	105	105	100				
Community Hosp B	99	99	100				

*89 of these 228 deaths were included in the Census of Deaths

HBD>24 hrs: refers to hospital based deaths after twenty-four hours length of stay. AE<24 hrs: refers to deaths in Accident & Emergency with twenty four hours length of stay. BID: refers to patients whom were brought in death to the hospital.

3.2.2 Sample for Census of Deaths

The sampling frame information compiled on patient sex, patient age, presenting complaint, cause of death and length of last hospital stay formed the study census.

However in one of the acute hospitals, with regard to hospital death after 24 hours length of stay, details could only be given for a stratified sample. This equated to information on 89 of 228 deaths that occurred over the year timeframe in this hospital. Data however was provided for all deaths in Accident and Emergency within twenty-four hours and for those who were brought in dead to “Acute Hospital B”. Therefore of the 941 deaths in the sampling frame, 802 (85%) were included in the census of deaths (Table 9).

Table 9: Number of deaths included in the census and sample for survey of end-of-life care

	All types		HBD > 24hrs		AE < 24hrs		BID	
	Census	Survey Sample	Census	Survey Sample	Census	Survey Sample	Census	Survey Sample
All Sites	802	374	430	374	70	0	302	0
Acute Hosp A	316	97	137	97	15	0	164	0
Acute Hosp B	282	80	89	80	55	0	138	0
Community Hosp A	105	105	105	105				
Community Hosp B	99	92	99	92				

3.2.3 Sample Size for Survey

The study population for the family views of end-of-life care survey were the contact persons of patients who had died over a one year period in the acute hospitals and over a two year period in the community hospitals. The 802 deaths in the study census which incorporated full sampling frame information were used as the basis to generate a sample for the survey of end-of-life care.

Exclusion criteria were applied to the 802 deaths to form the study sample. Exclusion criteria were:

Contact persons:

- who were less than 18 years of age
- who had been bereaved for less than four months
- who had complained about the death
- for whom full contact information was not available
- to whom it would be insensitive to send information about the research¹

Contact persons of ***patients:***

- who were less than 18 years
- who spent less than 24 hours in the hospital
- who were dead on arrival
- who died by suicide
- who had a sudden death¹

¹*Comparison of presenting complaint with cause of death and use of local hospital knowledge was used to assess the criteria of suddenness and sensitivity.*

After the exclusions were applied, 46.6% (N=374) of the census deaths were included in the sample for the survey of end-of-life care. The figure 374 represents 87.0% of the deaths that occurred in hospitals after twenty-four hours length of stay.

3.2.4 Procedure for contacting potential participants

An information pack about the study was posted to the contact person from the hospital premises. This included (1) a letter of information from the Hospital Manager and/or Director of Nursing (2) a consent form and (3) a research study information leaflet. The letter of information introduced the study and invited consent to receive study information. The consent form requested potential participants to consent to receive the postal questionnaire and to allow the Hospital to provide the RCSI researchers their contact details. The study information leaflet formed questions and answers about the research and included bereavement support details.

The RCSI researchers send postal questionnaires to those who consented to receive one. The questionnaire was accompanied by a letter of information from the researchers, a further copy of the study information leaflet and a stamped addressed envelope. Questionnaires were returnable to the RCSI. A follow up letter was sent out following a six week reply period.

The letter of information from the researchers provided participants with the option to nominate another person to complete the questionnaire, if for any reason, they felt they were more appropriate to do so. Potential participants were also informed that the ideal person to complete the questionnaire was the person who was closest to and knew most about the care received by the patient in hospital

Those who do not return consent forms to the hospital were not contacted again in relation to the research.

3.2.5 Questionnaire Development

The questionnaire (Appendix One) was developed in consultation with the HfH Programme Team. The questionnaire needed to measure the study questions, HfH Programme themes, have high reliability and validity and be acceptable to bereaved relatives. Upon critical review of the literature and in order to meet these criteria, it was decided to use a version of the Family Evaluation of Hospice Care (FEHC) Survey plus adaptations.

Study Questions Criterium

A modified version of the FEHC was chosen because the instrument focus of evaluation was on the “quality of care”, including the processes and structure of care. This met with the study overall objective to evaluate the quality of end-of-life care from the perspectives of bereaved relatives. Use of the FEHC plus adaptations made it possible to evaluate high performance areas and areas requiring improvement. The survey question structure also enabled findings to be interpreted in terms of whether they met with patient/family preferences. The availability of a questionnaire constructed like this was important because at the stage of study research design, the HfH Programme standards for end-of-life care were not yet developed and finalised.

Coverage of HfH Programme Themes Criterium

The FEHC instrument is based on a conceptual model of patient-focused, family centred medical care, which focuses on the patient but also acknowledges the importance of the family in care of the dying (Connor et al., 2005). Under this model, a health provider offers excellent end-of-life care when it 1) provides the desired physical comfort and emotional support, 2) supports shared decision-making, 3) treats the patient with respect, 4) attends to the needs of the family for emotional support and the needed information and 5) co-ordinates care effectively (Teno et al., 2001). The instrument was assessed to see if it measured HfH programme themes.

Upon review of the HfH Programme Themes, specific sub-themes were developed (Table 10). A matrix of FEHC questions labelled by (a) HfH themes and subthemes and by (b) instrument domains and sub-domains was developed and used to assess FEHC suitability for inclusion in the study. The FEHC was chosen because it had a good coverage of the themes of integrated care and communication and covered the theme of patient autonomy somewhat. Additional questions were added to measure the sub-themes of breaking bad news, awareness of dying, environment of death and family presence at time of death.

Table 10: HfH Programme core themes and sub-themes:

Integrated Care	Communication	Design & Dignity	Patient Autonomy	All themes
a) Symptom control*	a) Information – treatment*	a) Respect/Dignity*	a) ACP – treatment preferences*	a) Quality of care*
b) Symptom experience*	b) Information – supports*	b) Place of death**	b) ACP – funeral***	b) Quality of death***
c) Spiritual wellbeing*	c) Information – condition*	c) Privacy**		
d) Psycho-social supports*	d) Information – expectations*	d) Environment of death**		
e) Continuity of care*	e) Awareness of dying**	e) Family presence at time of death**		
f) Relatives' care of patient*	f) Breaking bad news**	f) Mortuary facilities***		
g) Healthcare costs***		g) Hygiene***		
h) Bereavement support***				

* Denotes that the FEHC measures these themes

** Denotes the themes in which questions were added to form the FEHC plus adaptations

*** Denotes HfH subthemes which were not measured

Reliability and Validity Criterium

As demonstrated in the literature review section, the FEHC was validated in a number of studies, however no studies were found that used the FEHC in a hospital setting.

Acceptability to Bereaved Relatives Criterium

The questionnaire was piloted with people who have had experience of bereavement (n=5) and with other researchers (n=5). The questionnaire was then finalized following feedback from the pilot participants, HfH Programme team and ethics committees.

3.2.6 Data analysis

Data was analysed using the Statistical Software Package SPSS. Analysis of survey data was primarily through the formation of domain and problem scores.

Domain Score

For each domain, a domain score was calculated. The question items within each domain has one “desirable answer” and the remaining answers are considered “negative responses”. In this analysis, the domain score is presented as the average of desirable answers within each domain. Domain scores are represented as a percentage, the higher the percentage the better the hospital performance on this aspect of care.

Problem Score

Within each domain, problem scores are also calculated. These sum the negative responses to individual questions and represent opportunities to improve care.

3.2.7 Ethical considerations

The study received ethical approval from the ethics committees associated with each hospital site and from the Royal College of Surgeons in Ireland (RCSI), Research Ethics Committee. The study proceeded only when ethical approval was received from each of the four pilot sites and from the RCSI REC. The length of time between initial ethics application and final approval was nine months (Table 11). The sensitivity of the research subject and method accounted for the extended length of time for ethical approval.

Table 11: Length of time and number of reviews involved in obtaining ethics approval

	Time between submission and ethical approval	Number of reviews	Type of Review	
			1 st Submission	2 nd Submission
<i>RCSI</i>	9 months	2	Committee	Chairperson
<i>Acute Hospital A</i>	5 months	2	Committee	Committee
<i>Community Hospital B</i>	6 months	2	Committee	Committee
<i>Community Hospital A</i>	2 months	2	Committee	Chairperson
<i>Acute Hospital B</i>	6 months	2	Committee	Chairperson
Total timeframe/reviews	9 months	10	5 Committee	3 Chairperson 2 Committee

Ethical issues specific to this study were similar to those of other studies outlined in the literature review. These included the acceptability of using postal questionnaires, the appropriate time frame between bereavement and research contact and the provision of bereavement support. Following guidance from the ethics committees, ethical issues specific to this study, were the right of access to deceased patients files to obtain the contact details of the contact person and the requirement for an “opt in” rather than an “opt out” consent mechanism.

Acceptability of using postal questionnaires

While postal questionnaires have been found to be an acceptable method of conducting bereavement follow back surveys (Addington-Hall et al, 1998; Lecouturier et al, 1999), there was a concern that some potential participants may have found being requested to complete a questionnaire about the dying experience of a relative or friend unacceptable. Hence potential participants were approached in a sensitive manner. Although it is not standard practice to precede the questionnaire with a letter requesting consent to receive it, this approach was adopted to minimize the likelihood of causing distress to the recipient.

Time between bereavement and contact with relative

As demonstrated in the literature review section, there has been a lack of standardisation regarding the appropriate time interval after the death to contact relatives about research. Other similar studies in Ireland contacted relatives at time intervals ranging from at least seven months (Keegan et al., 1999) to at least 12 months (St Vincent's Palliative Care Group, 2007). Studies from other countries contacted relatives at numerous time intervals ranging from at least one month to at least one year. For this study, the researchers advocated that this time period be three months, however upon the advice of the ethics committees this was extended to four months.

Provision of bereavement support

Another ethical consideration was the potential discomfort or distress to participants in being contacted in relation to the research and/or in reflecting upon the quality of end-of-life care. The study information leaflet provided the contact details for the Personal Counselling Institute (PCI) and where available the contact details of the hospital bereavement counselor or pastoral care worker. Each bereavement support person/agency was consulted with about the research before the information was sent to bereaved relatives.

Right of access to deceased patients files to obtain the contact details of the contact person

This research was conducted by RCSI academics, on behalf of the HfH Programme, and not by hospital employees. While two of the hospital sites (one acute and one

community) were participating in the HfH Programme and two were not. Therefore a question arose regarding the right of access to deceased patient files to obtain the contact details of the contact person. This study approach was for hospital staff to compile an anonymised sampling frame without any identifying information from individuals and that the researchers would only have access to contact person names with their consent. The study protocol was submitted to the Office of the Data Protection Commissioner and was deemed to be in accordance with the Data Protection Act and received all the appropriate ethical approvals.

Opt In versus Opt Out methods of consent

One proposed method of obtaining consent was to ask people to make contact (through a freephone number to the hospital) to opt out of the study. However, given the sensitivity of the research topic and without wanting to put undue burden on potential participants, it was decided with guidance from the ethics committees to choose an “opt in” consent mechanism. This meant that if potential participants did not fill in the consent form, to receive the questionnaire and to allow their contact details to be passed on to the RCSI Researchers, they would not be contacted again in relation to the research.

4 Census of Deaths in Two Acute and Two Community Hospitals

4.1 Introduction

The census of deaths provides details about the number and types of deaths that occurred in the hospitals over the study time period. The census includes details about demographic characteristics, presenting complaints, causes of death and length of last hospital stay.

4.2 Census of deaths

This section describes the census for all deaths and also for deaths after twenty-four hours length of stay, for deaths in Accident and Emergency within twenty-four hours length of stay and for deaths external to the hospital. Information regarding the latter type of death refers to persons who were brought in dead (BID data) and these occurred within the acute hospitals only.

4.2.1 Census of all deaths

- Of 802 deaths, 59% were male and 41% were female. There were more male (61%) than female (39%) deaths in the acute hospital group. However there were an approximately equal number of male (51%) and female (49%) deaths in the community hospital group.
- Overall, approximately half (47%) were aged 74 years or under. In the acute hospital group, 60% were aged 74 years or under. Whereas in the community hospital group, the majority (N=182; 89%) were aged 75 years plus.
- Of the 598 deaths across the acute hospital group, over half (51%) were patients who were brought in dead to hospital. Over one third (38%) were patients who had died in hospital after at least 24 hours length of stay, and 12% were patients who had died in the Accident and Emergency (AE) within twenty-four hours of arrival. In the community hospital group, all deaths (N=204) were of patients who had died in hospital within twenty-four hours.

4.2.2 Census of deaths after twenty-four hours length of stay

This section describes the census of deaths after twenty-four hours length of stay. The census includes details about demographic characteristics, location of death, presenting complaints, causes of death and length of last hospital stay.

4.2.2.1 Demographic characteristics

- Of the 430 deaths, 50% were male and 50% were female.
- Over three quarters (76%) were aged 75 years and over. Two thirds (65%) of patients who died in the acute hospital group and 89% of patients who died in the community hospital group were aged 75 years and over.

4.2.2.2 Location of death

- The majority (N=370; 90%) died in a hospital ward or room, 9% died in a specialized unit and 1% died in another part of the hospital.

4.2.2.3 Presenting complaints

- Data was provided on the presenting complaints upon last admission to hospital for 80% (n=343) of the 430 deaths. For each death one or more presenting complaints were provided.
- The presenting complaints were analyzed to form three broad categories – physiological, mental health and functional complaints (Table 12).

Table 12: Categorisation and examples of presenting complaints upon last admission to hospital

Types of Complaints:	Common examples:
Physiological	Cancers, pain, chest pain, shortness of breath, liver disease, stroke, chest infection, weakness, collapse, fractures, pneumonia, vomiting, falls, Parkinson's disease.
Mental health	Bipolar affective disorder, cognitive impairment, Alzheimer's Disease, confusion, depression, dementia, Parkinson's disease, schizophrenia.
Functional	Decreased mobility, Parkinson's disease.

- Overall most patients (92%) presented with physiological complaints and less presented with mental health (16%) and functional (6%) complaints. This trend was similar for the acute hospital group. However, the community hospital group had a higher rate of mental health and functional complaints:
 - Of 192 deaths in the acute hospital group, 98% (n=189) included physiological complaints; 4% (n=8) mental health complaints and 1% (n=2) functional complaints.
 - Of 151 deaths in the community hospital group, 83% (n=126) included physiological complaints; 30% (n=46) mental health complaints and 12% (n=18) functional complaints.

4.2.2.4 Cause of death

- Three of the four hospital sites provided data on the cause of death of the patient. This included the two acute hospitals and one of the community hospitals.
- The causes of death provided were analyzed to form nine core categories (Table 13).

Table 13: Typology of Causes of Death

<i>Causes of Death Categories</i>	<i>Examples:</i>
Cancers – all types	Carcinoma of the bladder, carcinoma of the colon, carcinoma of the endometrium, carcinoma of the pancreas, carcinoma of the prostate, carcinoma of the lymph glands, gall bladder cancer, bronchial carcinoma, non-small cell lung cancer, small cell lung cancer, gastric cancer
Dementia and Alzheimer's disease	Alzheimer's disease
Heart and circulatory diseases	Myocardial infarction, brain haemorrhage, cardiopulmonary arrest, cardiorespiratory arrest, ischemic heart disease, septicemia, congestive cardiac failure, refractory cardiac failure, intracerebral bleeding, hypertension, multi-organ failure, pulmonary oedema, ventricular fibrillation.
Infectious diseases	Gastro enteritis, sepsis, septicemia, bacterial meningitis, clostridium difficile infection, TB.
Kidney diseases	Chronic/acute renal failure, urinary tract infection.
Liver diseases	Hepatic encephalopathy, metastatic liver disease.
Lung and breathing diseases	Chronic obstructive airways disease, lung cancer, pneumonia, respiratory failure, respiratory tract infection.
Strokes	Cerebrovascular accident, ischaemic stroke, cerebrovascular disease.
Other	Diverticulitis, pancreatitis, thyrotoxicosis.

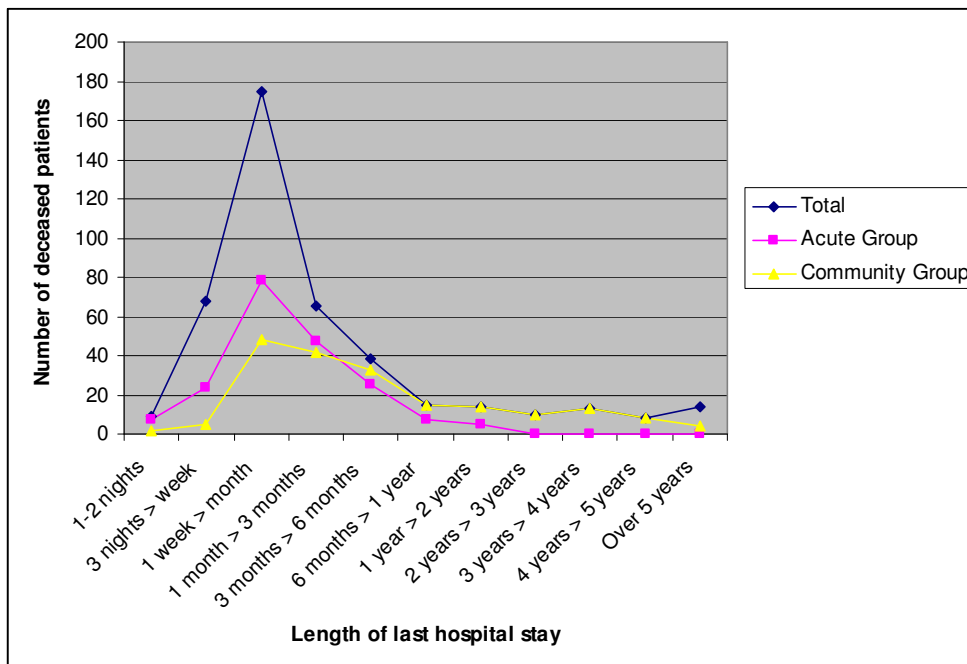
- Causes of death were provided for 283 (65.8%) of the 430 deaths. Often there was more than one cause of death specified:
 - Almost two thirds (60.8%) of patients died from lung and breathing diseases; one third (33.9%) died from heart and circulatory diseases and 18.7% died from cancer.
 - Less died from infectious diseases (9.9%), kidney diseases (9.9%), strokes (9.2%), liver diseases (2.5%). Dementia and Alzheimer's disease (1.8%) and other diseases (6.4%).
 - This trend was similar for the acute hospital group and the community hospital group.

4.2.2.5 Length of last hospital stay

Data on the length of the last hospital stay was provided for 429 of 430 deaths in hospital after twenty-four hours length of stay. Figure 4 outlines the length of last hospital stay for all hospitals and by hospital group.

- The most frequently occurring length of last hospital stay was for *more than one week but less than a month* (40.8%).
- Less than one in five had a last hospital stay was for less than one week's duration (18%). This included 2.1% with *1-2 nights* and 15.9% with *more than three nights but less than a week*.
- One in eight had a last hospital stay for more than three months but less than a year (12.4%). This included 8.9% with *more than three months but less than six months* and 3.5% with *more than six months but less than a year*.
- One in seven had a last hospital stay for over a year (13.8%).
- For almost two thirds (64.7%) of patients who died in the acute hospital group the length of last hospital stay was *more than one week but less than a month* (40.4%) or *more than one month but less than three months* (24.3%). In the community hospital group, for 44.1% the duration of last hospital stay was for these time periods. For 52.6% the duration of last hospital stay was for more than this.

Figure 4: Length of Last Hospital Stay



4.2.3 Census of deaths in Accident and Emergency within 24 hours length of stay

This section describes the census of deaths in Accident & Emergency within twenty-four hours length of stay. The census includes demographic characteristics and cause of death.

- Of 70 AE deaths in the acute hospital group, 72% were male and approximately half (49.2%) were aged under 64 years.
- The cause of death was heart and circulatory diseases in two thirds (65.0%) of cases. The other deaths arose from road traffic accidents (11.7%), lung and breathing diseases (8.3%), suicide (6.7%), cancers- all types (5.0%) and other causes (5.0%).
- In 80% (N=50) of cases a post mortem was carried out.

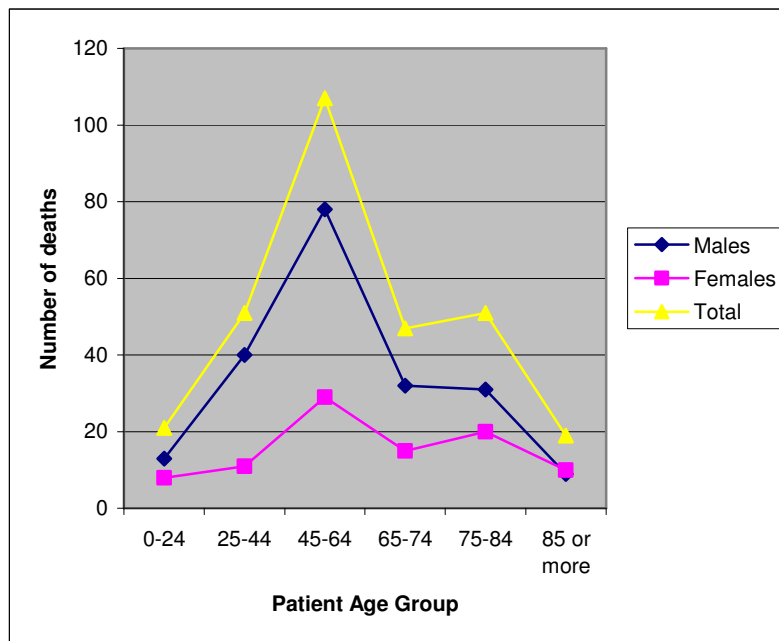
4.2.4 Census of BID data

This section provides a description of the demographic data regarding patients who were brought in dead to hospital. It includes details about demographic characteristics and cause of death. The findings refer to the two acute hospitals only.

4.2.4.1 Demographic characteristics

- Across the two hospitals, there were a total of 302 patients who were brought in dead to hospital. Over two thirds (68%) were male.
- Over three quarters (76.3%) of patients who were brought in dead were 74 years and under.
- Across all age groups, there were a higher number of males than females brought in dead to hospital, with the exception of those aged 85 years or more (Figure 5).

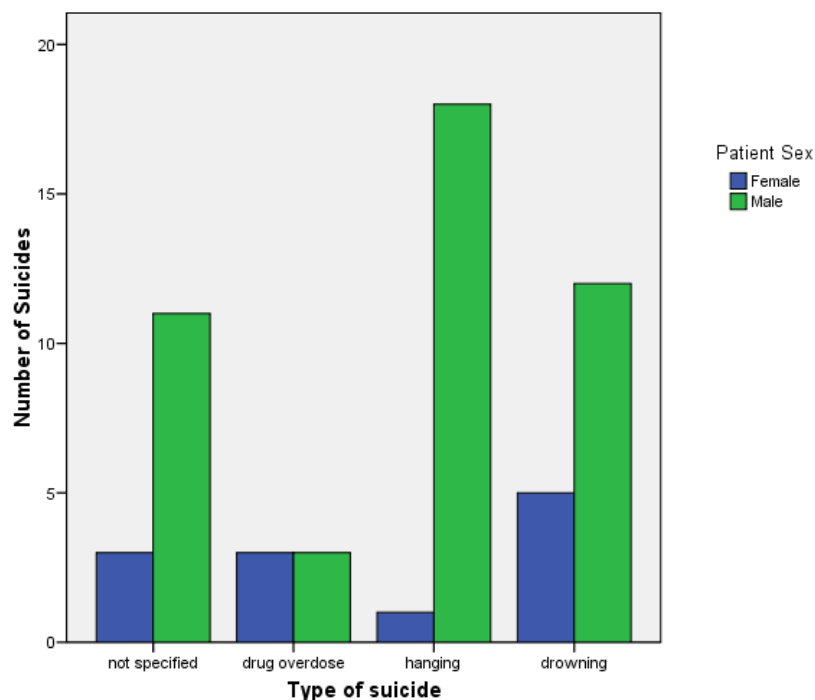
Figure 5: Number of patients brought in dead to hospital by age group and sex



4.2.4.2 Cause of death by demographic characteristics

- The most frequent cause of death among those who were brought in dead to hospital were heart and circulatory diseases (37.3%), suicide (29.0%) and other causes (19.7%). The other category included causes of death such as asphyxia, alcohol intoxication, falls, sudden death syndrome and accidental deaths.
- Of the two leading causes of death (heart and circulatory diseases and suicides) there were a higher number of male than female deaths across each age group. Among the other disease categories, the ratio between male and female deaths varied across the age groups.
- Of deaths arising from heart and circulatory diseases, the highest number (n=38;53.0%) were those aged between 45 and 64 years.
- Of deaths arising from suicide (N=56), the highest number (n=22; 38.6%) were those aged between 25 and 44 years. Approximately two thirds (64.3%) of the suicides were from hanging (33.9%) or drowning (30.4%). The type of suicide for 25% was undescribed and 10.7% were from a drug overdose. The type of suicide did not vary by agegroup. There was a gender difference in types of suicide however (Figure 6). Males were more likely than females to commit suicide by hanging; 18 of the 44 (41%) male suicides were from hanging while one of the 12 (8%) female suicides was from hanging.

Figure 6: Number and type of suicide by patient sex



- Details on whether a post mortem was carried out were provided for 299 of the 302 BID deaths. A post mortem was carried out for the majority (84.8%; N=256) of the deaths.

4.3 Discussion

There was a broader categorisation of types of death in the acute hospitals

The acute hospitals provided care for three core categories of dying; deaths in hospital after twenty-four hours length of stay, deaths in accident and emergency within twenty-four hours length of stay and for deaths external to the hospital. In comparison, the community hospitals did not provide AE services or services to those who die outside the hospital.

There were more male than female deaths in the acute hospitals

There were more male than female deaths in the acute hospitals, but an equal number of male and female deaths in the community hospitals. Across both hospital types there were no gender differences in the number of males and females who died in hospital after twenty-four hours length of stay. However, a higher number of males than females were brought in dead and died in accident and emergency within twenty-four hours.

There was a greater heterogeneity of age groups among those who died in the acute hospitals

Overall, the majority of those who died in the community hospitals and in the acute hospitals after 24 hours length of stay were aged 75 years and over. Conversely, the majority of those who died within twenty-four hours length of stay in Accident and Emergency and who were brought in dead to hospital were aged less than 75 years.

There was a greater diversity of categorisation of presenting complaint upon last admission to hospital among those who died in community hospitals

Across both hospital types, the majority of patients presented with a physiological complaint upon last admission to hospital. However, a higher number of patients in the community hospitals than acute hospitals presented with mental health and functional complaints.

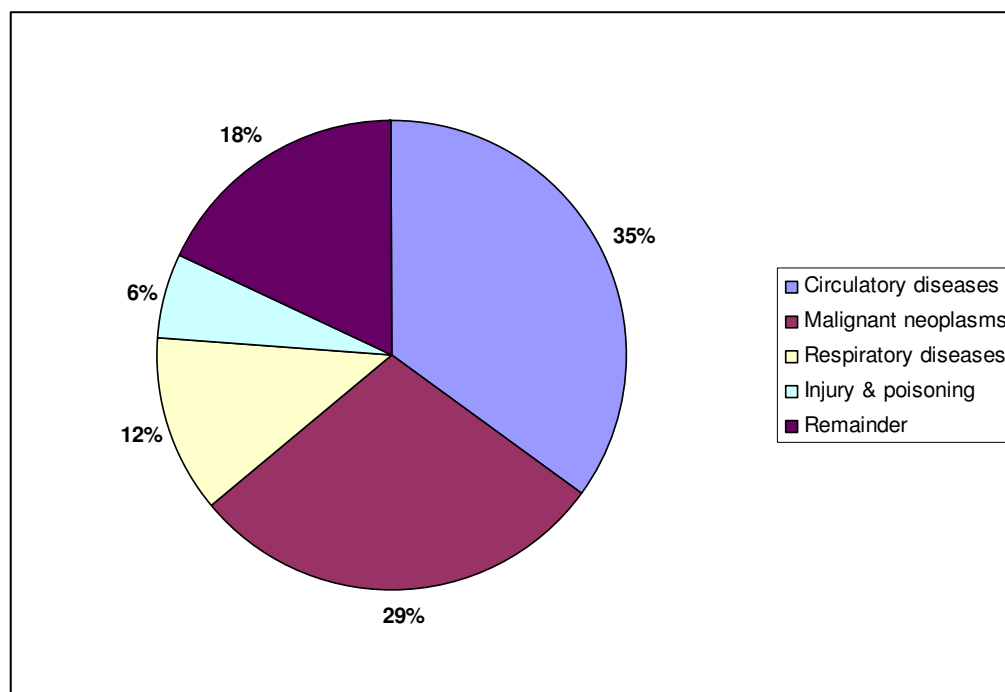
The leading cause of death was lung & breathing diseases among those who died in hospital after twenty-four hours length of stay. Heart & circulatory disease was the leading cause of death among those who died in Accident & Emergency within twenty-hours and among those who were brought in dead.

Across both hospital types after twenty-four hours length of stay, the leading cause of death was lung and breathing diseases followed by heart and circulatory diseases. The leading causes of death in Accident and Emergency within twenty four hours length of stay were heart and circulatory disease followed by road traffic accidents. The leading cause of death among those who were brought in dead to hospital were heart and circulatory diseases followed by suicide. The most common types of suicide were from hanging or drowning.

These figures contrast with national data on principal causes of death for the general population from the Central Statistics Office (CSO). Between 1998 and 2006 the principal cause of death among the general population were diseases of the circulatory system, followed by malignant neoplasms (CSO, 2008). Figure 7 indicates the principal causes of death for the year 2008 with respiratory diseases being ranked third. However caution should be utilized in interpreting these data, the researchers in this study did not use the International Classification of Diseases, Version 10 (ICD10) to classify the causes of death, as is the approached used by the Central Statistics Office (CSO). Also the CSO moved from utilizing the ICD9 to ICD10 in 2007 and they have noted that a significant drop in the number of deaths from pneumonia and bronchopneumonia have been observed in some countries after moving to ICD10.

The findings regarding the higher number of male than female suicides reflect the national statistics. In 2008, there were 424 male deaths and 92 female deaths from suicides. These figures represented 1.5% and 0.7% of the total male and female deaths for the year (CSO, 2008).

Figure 7: Principal causes of death in Ireland for 2008



Total number of deaths=28,192

On average the length of last hospital stay was shorter in acute hospitals than in community hospitals

For almost two thirds of patients who died in the acute hospitals the length of last hospital stay was *more than one week but less than a month* (40.4%) or *more than one month but less than three months* (24.3%). For 52.6% in the community hospital group the duration of last hospital stay was for more than these time periods.

4.4 Conclusion

In conclusion, the census of deaths describes the different types of deaths hospital staff provided care for over the study time frame. The information provided in this chapter is the larger context upon which services for death and dying are provided. The findings from the census and the survey (views of hospital based deaths after twenty-four hours) are further discussed in the executive summary.

5 Family Views of End-of-Life Care in Acute and Community Hospitals

5.1 Introduction

The section provides the results of the family views of end-of-life care survey which was conducted in two acute and two community hospitals. The results concern (1) factors affecting consent to receive the questionnaire, (2) questionnaire response rates, (3) participant demographic characteristics and (4) survey findings.

5.2 Factors affecting consent to receive the questionnaire

Of the 374 sample size, 37.8% consented to receive the questionnaire. This section discusses how patient, contact person, hospital and research method factors affected consent to receive the questionnaire.

5.2.1 Patient factors

- A higher number of persons consented in cases where they were the contact person for a deceased male (40.9%) than for a deceased female (35.1%). This trend was similar for the acute and community hospital groups.
- Those who consented were the contact persons for deceased patients aged between 45 and 85 years or more.

5.2.2 Contact person factors

- Females were more likely to consent to receive the questionnaire than males. Of 209 female and 165 male contact persons, 45.5% and 28.4% consented to receive the questionnaire respectively. This finding was similar for the acute and community hospitals groups (Table 14).
- Contact persons were categorised according to their relationship with the deceased patient. Overall, the highest consent rates were from contact persons who were the son or daughter (44.1%) of the deceased patient. This was followed by spouses (36.6%), other relatives, such as nieces or nephews (36.2%) and siblings (29.1%).
- These trends differed among the acute and community hospital groups. In both groups, the highest consent rates were from the contact persons who were the son or daughter of the deceased patient. In the acute group, this was followed by siblings

(34.6%) and spouses (30.8%). In the community hospital group, this was followed by spouses (47.2%) and other relatives (44.2%).

5.2.3 Hospital factors

- Likelihood to consent to receive the questionnaire was affected by hospital type. While the overall consent rate was 37.8%, there was a higher consent rate from contact persons of deceased patients who died in community hospitals (44.2%) than from those in the acute hospital group (31.1%).
- Within each category of length of last hospital stay, between one third and half of contact persons consented to receive the questionnaire.

Table 14: Factors affecting consent to receive the questionnaire

Study Sites:	All Sites			Acute Hospitals			Community Hospitals		
	SF ¹	CONSENT ²		SF	CONSENT		SF	CONSENT	
	N	N	%	N	N	%	N	N	%
Total Number of Deaths	374	142	37.8	177	55	31.1	197	87	44.2
Patient Sex									
Male	186	76	40.9	87	29	33.3	101	47	46.5
Female	188	66	35.1	90	26	28.9	96	40	41.7
Sex of Contact Person									
Male	165	47	28.4	69	14	20.3	96	33	34.4
Female	209	95	45.5	108	41	38.0	101	54	53.5
Time between Bereavement & Research Contact									
5-6 months	24	10	41.6	13	5	38.5	11	5	45.5
7-12 months	126	36	28.5	81	19	23.5	45	17	37.8
13-18 months	112	55	49.1	72	29	40.3	40	26	65.0
19-24 months	58	25	43.1	11	2	18.1	47	23	49.0
25-30 months	47	15	31.9	0	0	0	47	15	32.0
31-33 months	7	1	14.3	0	0	0	7	1	14.3

¹ The Sampling Frame refers to the number of people contacted to participate in the research

² Those who consented (CONSENT) refers to the number of people whom consented to receive the questionnaire.

5.2.4 Research method factors

- The length of time between bereavement and research contact had an impact on likelihood to consent to receive the questionnaire.
- Overall, the highest proportion of contact persons consented to receive the questionnaire when they had been bereaved for 13-18 months prior to being contacted to participate in the research. This finding also applied to the acute hospital and community hospital groups.

5.3 Questionnaire Response Rates

There was an 83.1% (N=118) response rate among those who consented to receive the questionnaire (N=142) (Table 15). This figure represented 31.6% of the sample size (N=374). Of those who consented, there was a higher response rate among the acute hospitals (91.0%) than the community hospitals (78.2%). However as a representation of the sample size, there was a higher response rate among the community hospitals (34.5%) than the acute hospitals (28.2%).

Table 15: Sampling frame, consent and response rate details

	All hospitals		Acute		Community	
	N	(%)	N	(%)	N	(%)
Total Sampling Frame	430		226		204	
Sample that met inclusion criteria for requesting consent	374		177		197	
Consent rate to receive questionnaire	142	(38.0)	55	(31.1)	87	(44.2)
Response Rate ¹ (¹ questionnaires returned as a percentage of those who consented to receive questionnaire, N=142)	118	(83.1)	50	(91.0)	68	(78.2)
Response Rate ² (² questionnaires returned as a percentage of the sampling frame, N=374)	118	(31.6)	50	(28.2)	68	(34.5)

5.4 Demographic Characteristics of Respondents

The study results represent the views of fifty contact persons (42.4%) of patients who died in the acute hospital group and of sixty-eight contact persons (57.6%) of patients who died in the community hospital group. This section details the demographic characteristics of the deceased patients and respondents.

Patient Characteristics

- Over half (54.7%) of the patients were male (Table 16).
- Overall, the most common age range for deceased patients was between 75-84 years (42.4%). The age profile of patients was younger in the acute hospital group than the community hospital group. Two out of three patients were aged over 75 years in the acute hospital group compared to nine out of ten patients in the community hospital group. In addition, 26% of those who replied were relatives of patients aged 85 or more in the acute hospital group compared to 45.5% in the community hospital group.
- Overall the most common illnesses/diseases that caused patients' deaths were cancers (24.8%), lung and breathing diseases (20.5%), frailty and decline due to old age (15.4%) and heart and circulatory diseases (14.5%). These diseases were among the top four common causes of death in the community hospital group and with the exception of "frailty and decline due to old age" in the acute hospital group also. Strokes were the fourth most common cause of death in the acute hospital group.
- Overall the most common length of last hospital stay reported by respondents was 1-3 months (27.4%).
- In comparison to the community hospital group, patients in the acute hospital group tended to have a shorter length of stay. The most common lengths of stay in the acute hospital group were 3-7 days (35.4%) and 8-14 days (31.3%). Other durations included 1-2 days (4.2%), 15-29 days (12.5%), 1-3 months (14.6%) and over two but less than three years (2.1%). The most common lengths of stay in the community hospital group were 1-3 months (36.9%) and 4-6 months (20.0%). Other durations included 8-14 days (3.1%), 15-29 days (4.6%), 7-9 months (9.2%), 10-12 months (3.1%) and the percentage was 23.1% for a range of time frames greater than a year and up to eight years.

Table 16: Deceased Patient Characteristics

	Overall		Acute		Community	
	N	%	N	%	N	%
Sex of Patient						
Male	64	54.7	26	52.0	38	56.7
Female	53	45.3	24	48.0	29	43.3
Agegroup of Patient						
25-44	0	0	0	0	0	0
45-64	9	7.8	7	14.0	2	3.0
65-74	15	12.9	10	20.0	5	7.6
75-84	49	42.2	20	40.0	29	43.9
85 or more	43	37.1	13	26.0	30	45.5
Cause of Death						
Frailty and decline due to old age	18	15.4	2	4.0	16	23.9
Dementia and Alzheimer's disease	10	8.5	2	4.0	8	11.9
Cancers all types	29	24.8	12	24.0	17	25.4
Heart and circulatory diseases	17	14.5	7	14.0	10	14.9
Lung and breathing diseases	24	20.5	14	28.0	10	14.9
Liver diseases	1	0.9	1	2.0	0	0
Strokes	9	7.7	5	10.0	4	6.0
Infectious diseases	1	0.9	1	2.0	0	0
Other diseases	8	6.8	6	12.0	2	3.0

Respondent Characteristics

- Respondents were immediate family members (i.e. spouse, partner, child or sibling) in the majority (82.7%) of cases. Approximately two thirds were female (66.7%) and were aged between 45-64 years (62.8%) (Table 17).
- The age profile of respondents was younger in the acute hospital group than in the community hospital group. One in five was aged over 65 years in the acute hospital group in comparison to one in three in the community hospital group.
- At the time of responding to the questionnaire, those whom returned questionnaires had been bereaved for a range of time periods including 7-12 months (28.7%), 13-18 months (41.7%), and over 19 months (29.6%).
- Those who returned the questionnaire tended to have been bereaved for longer in the community hospital group than in the acute hospital group. For example, of those who replied, 44.3% in the community hospital group and 10.4% in the acute hospital group had been bereaved for 19 months or more. This was largely a

reflection of the research design. The sampling frame was for one year in the acute hospital group and for two years in the community hospital group.

Table 17: Respondent Characteristics

	Overall		Acute		Community	
	N	%	N	%	N	%
Sex of Respondent						
Male	39	33.3	16	32.0	23	34.3
Female	78	66.7	34	68.0	44	65.7
Age group of Respondent						
25-44	11	9.3	4	8.3	7	10.8
45-64	71	62.8	34	70.8	37	56.9
65-74	19	16.8	4	8.3	15	23.1
75-84	12	10.6	6	12.5	6	9.2
Relationship of respondent to deceased						
Spouse	22	18.9	11	22	11	16.7
Partner	2	1.7	2	4.0	0	0
Child	61	52.6	25	50.0	39	54.5
Sibling	11	9.5	7	14.0	4	6.0
Niece/nephew	11	9.5	1	2.0	10	15.2
Other relatives	9	7.8	4	8.0	5	7.6
Length of time between bereavement and research contact						
7-12 months	33	28.7	16	33.3	17	25.0
13-18 months	48	41.7	27	56.3	21	31.3
19-24 months	24	20.9	5	10.4	19	28.4
25-30 months	7	6.1	0	0	7	10.4
31-36 months	3	2.6	0	0	3	4.5

5.5 Survey Findings

This section presents the survey findings across the domains of care and HfH Programme themes. These domains include the Family Evaluation of Hospice Care (FEHC) domains plus adaptations (questions* added to ensure the questionnaire measured the HfH Programme themes). The findings are presented under the each of the HfH Programme Themes as well as under the heading care outcomes:

Patient Autonomy

- Provide patient autonomy
- Family preferences for place of death*

Integrated Care

- Attend to family needs for support
- Provide desired physical comfort and emotional support
- Provide co-ordination of care

Communication

- Attend to family needs for information
 - Inform and communicate about the patient
 - Provide information about symptoms
- Breaking bad news*
- Awareness of dying*

Design and Dignity

- Provide dignity and respect
- Family presence at the time of death*
- Environment of care*

Care Outcomes

- Overall satisfaction scale
- Overall quality of care

The presentation of survey findings deal with domain scores, problem scores and qualitative data. These are explained next.

Domain Score

For each domain, a domain score was calculated. The question items within each domain have one “desirable answer” and the remaining answers are considered “negative responses”. In this analysis, the domain score is presented as the average of desirable answers within each domain. Domain scores are represented as a percentage, the higher the percentage the better the hospital performance on this aspect of care. The average of the undesirable answers within each domain represents opportunities to improve care.

Problem Score

Within each domain, problem scores are also calculated. These sum the negative responses to individual questions and represent opportunities to improve care.

Qualitative Responses

The final part of the survey asked respondents to describe “care that was satisfactory” and “care that could have been done better”. The responses provided were analysed to form themes. These themes were relevant to some of the domains of care described above. The thematic data is presented with the relevant survey domain finding to provide deeper meaning to respondents’ evaluations of end-of-life care in hospitals.

5.5.1 HfH Theme: Patient Autonomy

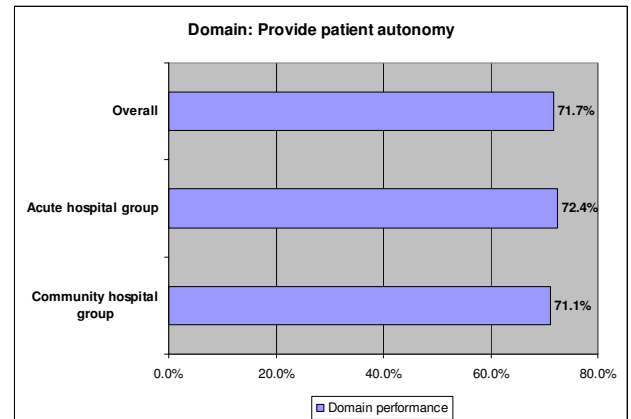
The focus of HfH Programme activities in the area of patient autonomy is on the rights of patients and on the importance of an ethical framework which supports hospital staff to become more informed, confident and collaborative in addressing the ethical and legal challenges that arise in the treatment and care of dying patients and their families (McKeown et al., 2010). The study results concerning patient/family autonomy regarding treatment preferences and choice of place of dying are presented next.

5.5.1.1 Provide Patient Autonomy

The domain score for “provide patient autonomy” for hospitals overall was 71.1%. This meant that on average there was an opportunity to improve care in 28.9% of cases. The overall domain scores for the acute hospital group (72.4%) and community hospital group (71.1%) were similar.

Table 18: Provide Patient Autonomy

A2: Hospital speak about patient's/ families' wishes for medical treatment (% Yes)	
Overall	49.6
Acute Hospital Group	53.1
Community Hospital Group	46.9
A3: Hospital do anything inconsistent with patients stated wishes (% No)	
Overall	93.7
Acute Hospital Group	91.6
Community Hospital Group	95.3



Respondents reported more positively in response to whether *hospital staff did anything inconsistent with the relatives previously stated wishes while dying* than to whether *hospital staff spoke to the patient regarding their wishes for medical treatment while dying*. This related to the finding that many respondents were unaware if hospital staff spoke to the patient or to other family members regarding their wishes for medical treatment. The problem score for the latter item was 46.9% in the acute hospital group and 53.1% in the community hospital group.

5.5.1.2 Choice of Place of Dying

Overall the majority (85.6%) were satisfied that the hospital was the right place for the patient to die, considering the patients needs in their final days (Table 19). However this figure was 92.6% in the community hospital group compared to 76% in the acute hospital group. Places that were considered more appropriate among those who were dissatisfied were at home (50%), hospice care (25%), or other (25%) e.g. nursing home care or private hospital care.

Table 19: Respondents' views regarding Choice of Place of Dying

	Overall		Acute Hospitals		Community Hospitals	
	N	%	N	%	N	%
<i>Considering your relative's needs in her final days, are you satisfied that the hospital was the right place for her to die?</i>						
Yes	101	85.6	38	76	63	92.6
No	17	14.4	12	24	5	7.4
<i>If no, where would you have considered most appropriate?</i>						
Home	8	50.0	7	63.6	1	20.0
Hospice	4	25.0	2	18.2	2	40.0
Other ¹	4	25.0	2	18.2	2	40.0

5.5.2 HfH Theme: Integrated Care

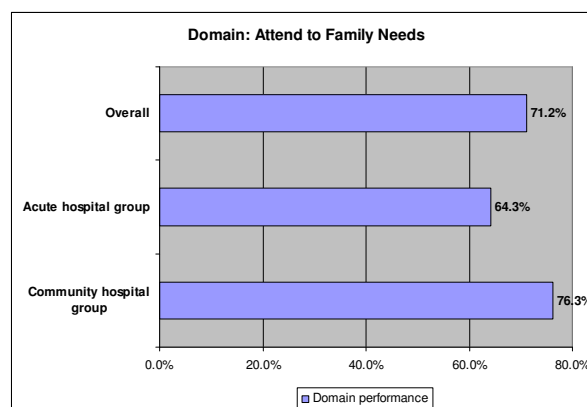
The purpose of the HfH Programme theme integrated care is to promote a more seamless, holistic and user-friendly care for the dying person and his or her family (McKeown et al., 2010). Findings regarding respondent views of hospital staff provision of religious and emotional support to families, the management of patients' symptoms and co-ordination of care are presented next.

5.5.2.1 Attend to family needs for support

The domain score for "attend to family needs for support" for hospitals overall was 71.2%. The domain score was higher in the community hospital group (76.3%) than the acute hospital group (64.3%) by over 10%.

Table 20: Attend to Family Needs for Support

E1: Hospital discussed religious and spiritual beliefs (% Yes)	
Overall	39.0
Acute Hospital Group	36.0
Community Hospital Group	41.2
E2: Right amount of religious/spiritual contact (% Yes)	
Overall	85.1
Acute Hospital Group	75.5
Community Hospital Group	92.3
E4: Hospital emotional support to family PRIOR to patient's death (% Right Amount)	
Overall	80.9
Acute Hospital Group	73.5
Community Hospital Group	86.4
E5: Hospital emotional support to family AFTER to patient's death (% Right Amount)	
Overall	79.7
Acute Hospital Group	72.0
Community Hospital Group	85.3



Less than half of respondents reported that hospital staff discussed their religious and spiritual beliefs with them. However, most respondents in the community hospital group reported they received the right amount of religious/spiritual contact (92.3%) and emotional support PRIOR to (86.4%) and AFTER (85.3%) the death. The figures for this in the acute hospital group were 75.5%, 73.5% and 72.0% respectively.

In addition to these findings, overall 83.9% of relatives reported that they felt the patient's personal and religious beliefs were taken into consideration by hospital staff. This figure represented the majority of respondents in the community hospital group (89.7%) and three quarters of those in the acute hospital group (76.0%).

Over one fifth (21.9%) of respondents (n=64) who provided comments regarding "care that was satisfactory" described the religious and emotional support provided to family members. Their comments showed that respondents valued when care and spiritual support was provided both to patients and family relatives. Of the respondents who provided comments on care that could have been done better (n=36), a small number (n=5) from the acute hospital group described a lack of empathy, emotional and religious support. A selection of respondents' comments is provided next.

Table 21: Care that was satisfactory - attend to family needs for support

<p><i>Community Hospital Group</i> <i>The staff were so good always caring, approachable and so helpful. I will always be so grateful to them, they cared for me as well.</i></p> <p><i>I have to say that the two nurses who were looking after my father that evening were wonderful, both to him and to me and my family. And afterwards, they did all they could to comfort us, which is something I will always remember.</i></p> <p><i>Acute Hospital Group</i> <i>A lady pastor visited and said beautiful prayers.</i></p> <p><i>When they saw me praying into my father's ear just after he died, they called a Chaplain who performed the formal rituals appropriate to the occasion. The Chaplain was great and we really appreciate that he was called after our father died.</i></p> <p><i>Some even cried with us. Personally, I cannot fault the doctors or nurses for their professional care.</i></p>
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In summary, the opportunity to improve care regarding "attending to family needs for support" was 28.8% in overall cases and 35.7% in the acute hospital group and 23.7% in the community hospital group.

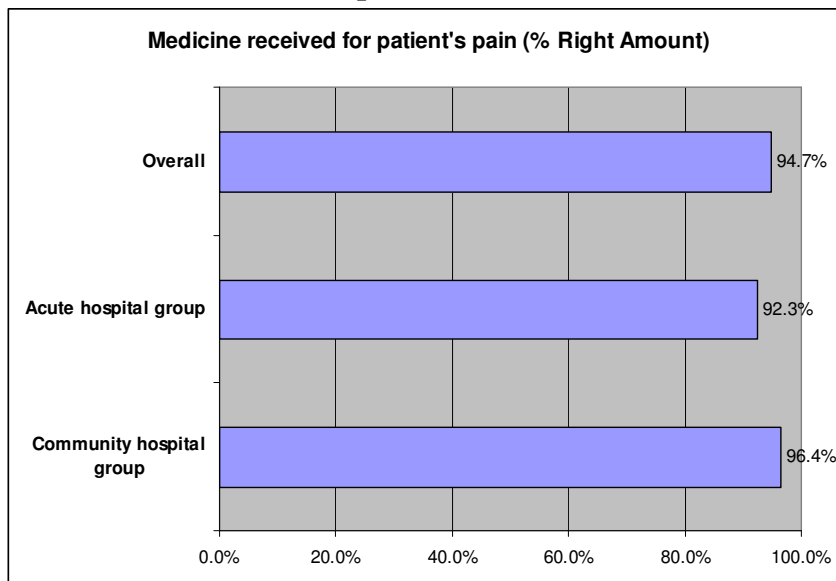
5.5.2.2 Provide desired physical comfort and support

The overall domain score for “the provision of desired physical comfort and support” was 86.3% and there was a higher domain score in the community hospital group (91.9%) than in the acute hospital group (76.1%). The following survey findings regarding this domain detail respondents’ views of how well hospital staff controlled pain, provided help for trouble with breathing and provided help with feelings of anxiety and sadness.

Pain Control

Overall, the majority of respondents (82.8%) reported that patients had pain or took medicine for pain while in hospital. This figure was representative of both the acute (83.7%) and community (82.1%) hospital groups. Across all groups, the vast majority of respondents reported that the patient received the “right amount” of treatment for pain (Figure 8).

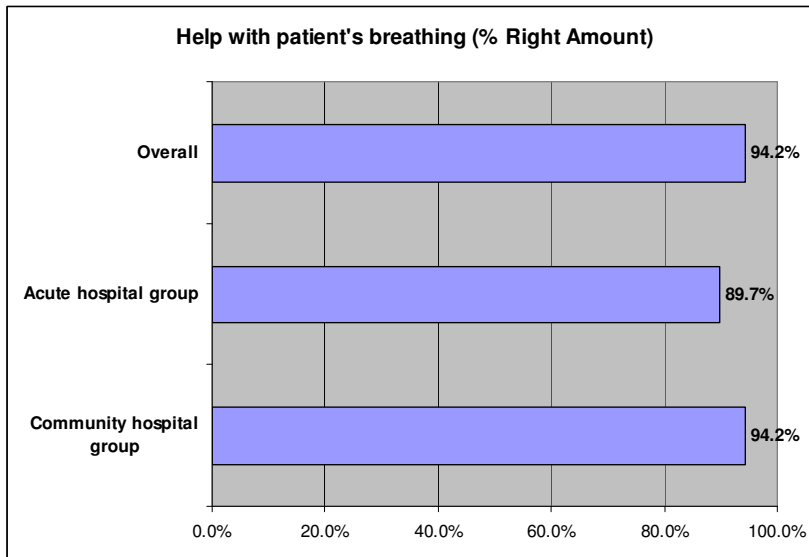
Figure 8: Respondents perceptions of whether the patient received the “right amount” of treatment for pain.



Shortness of Breath

Overall, 61.5% of respondents reported that patients had trouble with breathing while in hospital. While most respondents (80%) reported that the patient had trouble with breathing in the acute hospital group this figure was under half (47.8%) in the community hospital group. The majority of respondents across all groups reported that the patient received the “right amount” of help for trouble with breathing (Figure 9).

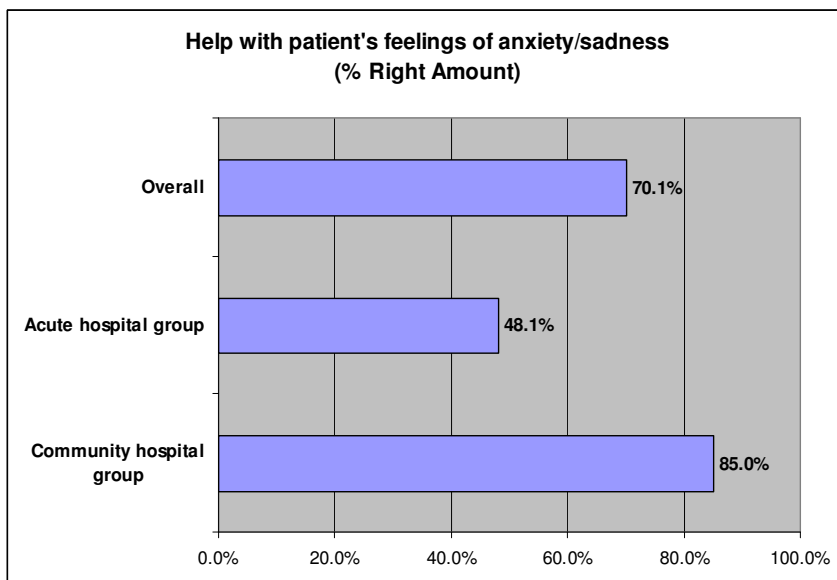
Figure 9: Respondents perceptions of whether the patient received the “right amount” of help for trouble with breathing.



Anxiety and/or Sadness

Overall, 61.4% of respondents reported that the patient had feelings of anxiety or sadness while in hospital. These figures were similar in the acute (64.6%) and community (59.1%) hospital groups. Overall 70.1% of respondents reported that the patient received the right amount of help in dealing with these feelings. However, under half (48.1%) of respondents felt that patients received the right amount of help in the acute hospital group compared to 85.0% in the community hospital group (Figure 10).

Figure 10: Respondents perceptions of whether the patient received the “right amount” of help for feelings of anxiety/sadness



In summary, the unmet needs scores for *pain control* were 5.3% overall, 7.7% in the acute hospital group and 3.6% in the community hospital group. The unmet need scores for *help for trouble with breathing* were 5.8% overall, 10.3% in the acute hospital group and 5.8% in the community hospital group. The unmet need scores for *help with feelings of anxiety and sadness* were 29.9% overall, 51.9% in the acute hospital group and 15% in the community hospital group.

Of respondents who provided comments in the acute hospital group, six respondents (26.1%) provided comments regarding the provision of desired physical comfort and support. Opportunities for improvement were in relation to diagnosis upon admission, the provision of pain relief and the appropriateness of treatment given to dying patients. A selection of respondents' comments is provided next.

Table 22: Care that could have been done better - provision of desired physical comfort and emotional support

"Pain medication already prescribed e.g. oromorph not always given as required – patient asked for it and was not given same, time passed and doctors had to be called when she became breathless and distressed then requiring IM morphine."

"Sending a Physiotherapist down to give physio – Mum died shortly afterwards."

"His consultant was on holidays and left specific instructions for 'traceva' to be administered. The family had to insist with his locum that the tarceva be discontinued and palliative care be increased as it was obvious to us at three days before his death he needed comfort not intervention."

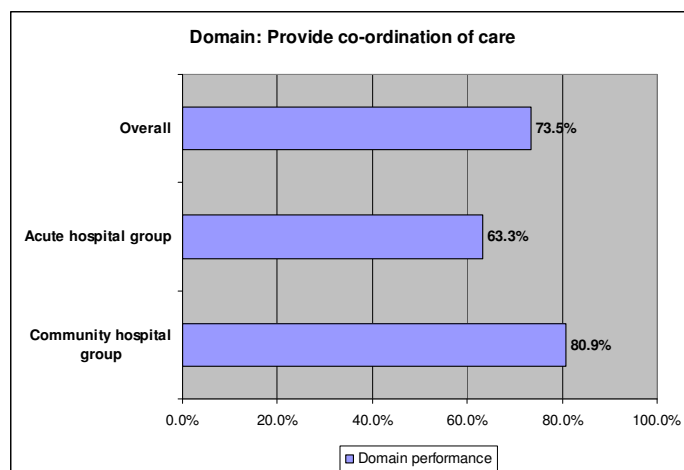
"During my mother's last days, I looked for palliative care and was told (privately) that this treatment was reserved for patients who were very ill with cancer."

5.5.2.3 Provide co-ordination of care

The domain score for “provide co-ordination of care” was 73.5% for hospitals overall. The domain performance was better by 17.6% in the community hospital group (80.9%) than in the acute hospital group (63.3%). Across both groups the highest opportunity to improve care was with regard to having one nurse identified as in charge of patient care.

Table 23: Provide co-ordination of care

F1: Hospital gave confusing or contradictory information about relative’s medical treatment (% Never)	
Overall	76.3
Acute Hospital Group	66.0
Community Hospital Group	83.8
F2: One nurse identified as in charge of patient care (% Yes)	
Overall	59.8
Acute Hospital Group	46.9
Community Hospital Group	69.1
F3: Problem with not knowing patient medical history (% No)	
Overall	84.5
Acute Hospital Group	77.1
Community Hospital Group	89.7



The qualitative data supported these findings. Of those who provided comments, twelve respondents (52.2%) from the acute hospital group and one respondent (7.7%) from the community hospital described aspects of co-ordination of end-of-life care that could have been done better. Some problems identified included lack of integration of services, lack of access to hospital services, delays in hospital admission, insufficient communication between hospital teams, insufficient care at weekends and at Christmas time and inappropriate delays in implementing decision-making regarding care. Some respondents also noted the importance of patients having a relative present to act as an advocate for their care. A selection of respondents’ comments is provided next.

Table 24: Care that could have been done better - improve co-ordination of care

<i>“Care excellent in hospital – greater care needed in management of patient at home and easier access to hospital services from home if required.”</i>
<i>“Lack of communication between medical team and palliative care team led to family receiving conflicting information prior to death.”</i>
<i>“I would also recommend the necessity of ones relatives to be present and involved in care and oversee its delivery.”</i>
<i>“No one in charge at the weekend – we were informed that no decisions could or would be made until after the weekend.”</i>
<i>“At critical times there was 24 hour delay in implementing doctors instructions e.g. reading x-rays for feeding tubes and blood transfusion”</i>

In summary, the opportunity to improve care regarding the domain “provide co-ordination of care” was 26.5% in all cases and 36.7% in the acute hospital group and 19.1% in the community hospital group.

5.5.3 HfH Theme: Communication

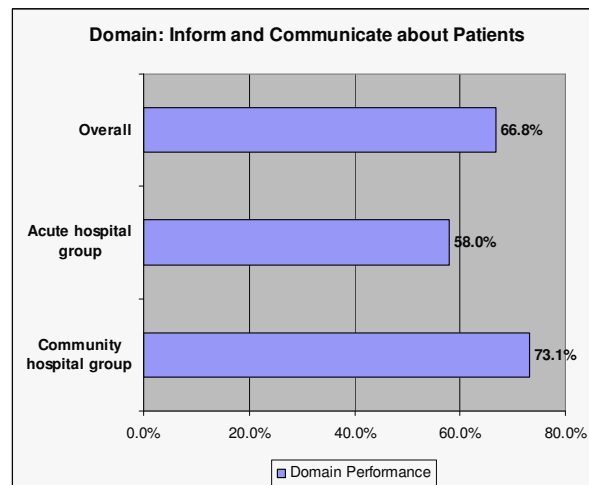
The purpose of the HfH Programme activities in the area of communication is to enhance the skills of staff to relate simply and warmly to patients while respecting their autonomy and preferences (McKeown et al., 2010). Study findings regarding respondents’ views of the (i) provision of information about the patient, (ii) provision of information on symptom management, (iii) provision of information to families on how to care for the patient, (iv) breaking bad news and (v) awareness of dying are presented next.

5.5.3.1 Inform and communicate about patient

The domain score for “inform and communicate about patient” for hospitals overall was 66.8%. The domain performance was 15% greater in the community hospital group (73.1%) than in the acute hospital group (58.0%).

Table 25: Inform and communicate about patients

D5: Family kept informed of patients condition (% Always)		
Overall		68.4%
Acute Hospital Group		55.1%
Community Hospital Group		77.9%
D6: Family received information on dying process (% Yes)		
Overall		58.3%
Acute Hospital Group		54.2%
Community Hospital Group		61.2%
D7: Family wanted more information on dying process (% No)		
Overall		73.7%
Acute Hospital Group		64.6%
Community Hospital Group		80.3%



Similar numbers of relatives in the acute (54.2%) and community (61.2%) hospital groups indicated that they had received *information on what to expect while their relative was dying*. However, most (80.3%) in the community hospital group were satisfied with the amount of information they had received compared to two thirds (64.6%) in the acute hospital group. In addition to this, over three quarters of relatives in the community

hospital group reported that they were always *kept informed of the patient's condition* compared to over half of relatives in the acute hospital group.

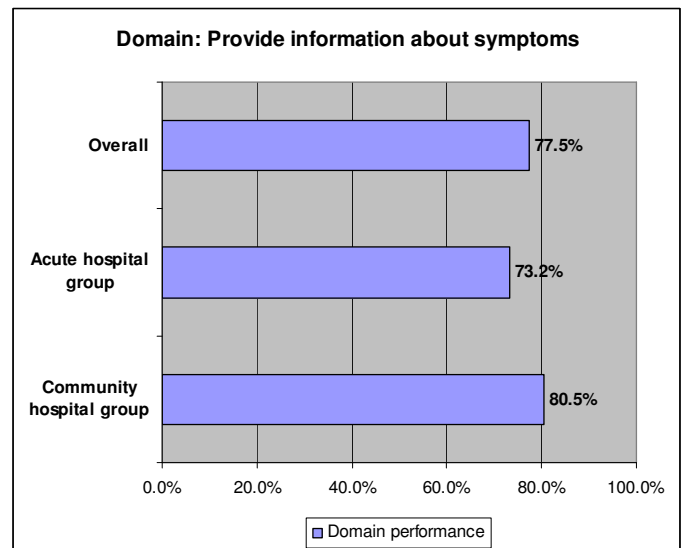
In summary, the opportunity to improve care regarding the domain “inform and communicate about patients” was 33.2% in all cases and 42.0% in the acute hospital group and 26.9% in the community hospital group.

5.5.3.2 Provide information about symptoms

The domain score for “provide information about symptoms” for hospitals overall was 73.5%. The domain performance was better by over 10% in the community hospital group (78.6%) than in the acute hospital group (66.7%).

Table 26: Provide information about symptoms

B3: Information given on pain management medications (% Yes)		
Overall		73.5%
Acute Hospital Group		66.7%
Community Hospital Group		78.6%
B4: More information wanted on pain management medications (% No)		
Overall		84.5%
Acute Hospital Group		73.2%
Community Hospital Group		92.9%
B7: Information given on treatment for breathing problems (% Yes)		
Overall		70.0%
Acute Hospital Group		70.0%
Community Hospital Group		70.0%
B8: More information wanted on treatment for breathing (% No)		
Overall		81.9%
Acute Hospital Group		82.9%
Community Hospital Group		80.6%



Respondents in both groups rated provision of information regarding breathing problems similarly. Seventy per cent of respondents in the acute and community hospital groups reported that they had received information on what was being done to manage their relative's trouble with breathing and approximately 80% reported that they were satisfied with the amount of information they had received.

However, 78.6% of respondents in the community hospital group compared to 66.7% in the acute hospital group reported that they had received information on pain management

medications. Most (92.9%) in the community hospital group were satisfied with the amount of information they had received compared to 73.2% in the acute hospital group.

For the acute hospital group, the qualitative data supported the finding that communication with families was an aspect of care requiring for improvement. Over half (n=12; 52.2%) of the 23 respondents in the acute hospital group who provided comments on “care that could have been done better” described issues relevant to the provision of information to families. However, this issue was not represented in the comments from respondents in the community hospital group.

Problem areas were lack of staff initiation of communication with families, delays in meeting with senior medical personnel, insufficient explanation of symptom management and of procedures for dying patients and their families. Examples of the latter include managing family expectations of the dying process, explaining do-not-resuscitate orders and facilitating family presence at the time of death. A selection of respondents’ comments is provided next.

Table 27: Care that could have been done better – provision of information to families.

<i>“Family were informed of relative progress by questioning staff/team. Team didn’t approach family.”</i>
<i>“Sometimes I felt when ward was very busy, staff avoided eye contact so as not to be asked for anything.”</i>
<i>“On my first appointment with the doctor in charge he appeared to have misleading information concerning my sister’s condition prior to being admitted. I did wonder could this have contributed to the final outcome.....I requested a meeting with the team and had to wait five days.”</i>
<i>“For future reference I feel that the Hospital should spend some time explaining procedures to family members and by that I mean what does “do not resuscitate mean”. I knew but my family members did not, so that it was I that explained it to them. Also, what happens when the person dies and what are the family to do. At all times, keep the lines of communication open and to be realistic in the care of the patient and their family.”</i>

In summary, the opportunity to improve care regarding the domain “provide information about symptoms” was 22.5% in all cases and 26.8% in the acute hospital group and 19.5% in the community hospital group.

5.5.3.3 Provision of information to families on how to care for the patient

Overall approximately half of respondents (N=60; 52.1%) indicated they participated in taking care of the patient while they were in hospital and the vast majority reported that they had enough instruction to do what was needed. These figures were representative of respondents in both the acute and community hospital groups. Overall 50% indicated they felt very confident in doing what they needed to do in taking care of their relative and this figure was also representative of respondents in the acute (45.8%) and community (52.8%) hospital group. Under half reported that they were “very confident” that they knew as much as they need to about the medicines being used to manage their relative’s pain, shortness of breath and other symptoms. More respondents in the community hospital group (50.0%) reported they were very confident than respondents in the acute hospital group (33.3%).

5.5.3.4 Breaking bad news

Overall, approximately three quarters indicated that the hospital team told them or another family member before the time of the death that the patient was likely to die soon. This figure was also representative of the acute and community hospital groups. Overall the majority (91.2%) reported that this information was shared in a sensitive way but less (71.4%) reported that there was enough privacy at this time. These figures were similar for the acute and community hospital groups.

Table 28: Respondent rating of breaking bad news

	Overall		Acute Hospitals		Community Hospitals	
	N	%	N	%	N	%
<i>Before the time of the death, did the hospital team tell you or another family member that your relative was likely to die soon?</i>						
Yes	87	75.7	38	76.0	49	75.4
No	28	24.3	12	24.0	16	24.6
<i>Was this information shared in a sensitive way?</i>						
Yes	83	91.2	33	82.5	50	98.0
Somewhat	7	7.7	6	15.0	1	2.0
No	1	1.1	1	2.5	0	0
<i>Was there enough privacy at this time?</i>						
Yes	65	71.4	29	70.7	36	72.0
Somewhat	17	18.7	7	17.1	10	20.0
No	9	9.9	5	12.2	4	8.0

5.5.3.5 Awareness of Dying

Overall less than half (41.0%) reported that the patient was aware they were dying and this figure was similar for the acute (44.0%) and community (38.8%) hospital groups. Across groups, approximately one quarter of respondents did not know if the patient was aware they were dying.

Overall approximately 28.9% believed that the patient would have liked to have known that they were dying. This figure was approximately one third in the acute hospital group (34.7%) and nearly half (46.2%) in the community hospital group.

Table 29: Awareness of Dying

	Overall		Acute Hospitals		Community Hospitals	
	N	%	N	%	N	%
<i>Was your relative aware that she was dying?</i>						
Yes	48	41.0	22	44.0	26	38.8
No	38	32.5	16	32.0	22	32.8
Don't Know	31	26.5	12	24.0	19	28.4
<i>Do you think she would have wished to know?</i>						
Yes	33	28.9	17	34.7	16	24.6
No	45	39.5	15	30.6	30	46.2
Don't Know	36	31.6	17	34.7	19	29.2
<i>Did the hospital team tell your relative that she was likely to die soon?</i>						
Yes	15	12.8	5	10.0	10	14.9
No	64	54.7	26	52.0	38	56.7
Don't Know	38	32.5	19	38.0	19	28.4
<i>Did you or any other family members/friends tell your relative that she was likely to die soon?</i>						
Yes	19	16.4	10	20.0	9	13.6
No	94	81.0	37	74.0	57	86.4
Don't Know	3	2.6	3	6.0	0	0

Few respondents (12.8%) reported that the hospital team told the patient that they were likely to die soon. Over half (54.7%) reported that the hospital team did not tell their relative and one third (32.5%) did not know. These findings were similar for the acute and community hospital groups.

In addition to these findings, overall, the majority of respondents (84.6%) felt “somewhat to very prepared” for the death of the patient. More relatives reported they felt prepared for the death in the community hospital group than in the acute hospital group. One in four felt not at all prepared in the acute hospital group compared to less than one in ten in the community hospital group.

Table 30: Feeling of preparation for the death.

	Overall		Acute Hospitals		Community Hospitals	
	N	%	N	%	N	%
<i>How prepared did you feel for the death of your relative?</i>						
Very prepared	44	37.6	14	28.0	30	44.8
Somewhat prepared	55	47.0	23	46.0	32	47.8
Not at all prepared	18	15.4	13	26.0	5	7.5

5.5.4 HfH Theme: Design and Dignity

The focus of activities for the HfH Programme Theme Design & Dignity is on providing peaceful and dignified surroundings which ensure the patient’s dignity and privacy, and offer a sense of psychological and spiritual support (McKeown et al., 2010). The survey research findings presented next include respondents’ views of (i) provision of dignity and respect, (ii) facilitating family presence at the time of death and (iii) environment of care.

5.5.4.1 Provide dignity and respect

Overall, three quarters of respondents indicated that the patients’ personal care needs were “always” taken care of as well as they should have been by the hospital team, while 84.5% indicated that the hospital team “always” treated the patient with respect. Respondents in the community hospital group rated these items more highly than relatives in the acute hospital group (Table 31).

Table 31: Dignity and respect

C1: Relatives personal care needs taken care of as well as they should have been by the hospital team (% Always)	
Overall	76.9%
Acute Hospital Group	67.3%
Community Hospital Group	83.8%
C2: How often the hospital team treated your relative with respect (% Always)	
Overall	84.5%
Acute Hospital Group	77.1%
Community Hospital Group	89.7%

5.5.4.2 Family presence at time of death

Overall nearly 60% indicated that hospital staff asked them if they wished to be present at the time of the death (Table 32). This figure was higher in the community hospital group (63.6%) than in the acute hospital group (53.1%). While across groups the majority wished to be present at the time of the death, less than half (48.5%) were actually present. More respondents were present at the death in the acute hospital group (62.0%) than in the community hospital group (48.5%).

Table 32: Family presence at the time of the death

	Overall		Acute Hospitals		Community Hospitals	
	N	%	N	%	N	%
<i>Did hospital staff ask you if you wished to be present at the time of the death?</i>						
Yes	68	59.1	26	53.1	42	63.6
No	47	40.9	23	46.9	24	36.4
<i>Did you wish to be present at this time?</i>						
Yes	109	94.8	48	98.0	61	92.4
No	6	5.2	1	2.0	5	7.6
<i>Were you actually present at this time?</i>						
Yes	33	48.5	31	62.0	33	48.5
No	35	51.5	19	38.0	35	51.5

5.5.4.3 Environment of care

Respondents rated the following aspects of the environment of care: (i) the type of room the patient died in, (ii) the physical environment of care and (iii) hospital facilities.

Type of room the patient died in

Overall, few respondents (22.6%) reported that the patient was offered a choice of room during their last hospital admission and this figure was similar for the acute (24.5%) and community (21.5%) hospital groups (Table 33). In relation to the type of room patients died in, overall the highest number died in a ward (63.6%) followed by a single room (25.4%), special unit (9.3%) or other (2%). In the community hospital group, approximately four in five patients died in a ward, while one in five died in a single room. In comparison in the acute hospital group, less than half died in a ward, one in three died in a single room and one in five died in a special unit.

Of those who did not have a single room, between 25% and 30% of respondents across groups indicated that the patient would have preferred a single room at this time. Furthermore, across groups, approximately 50% of respondents indicated that they themselves would have preferred if the patient had a single room.

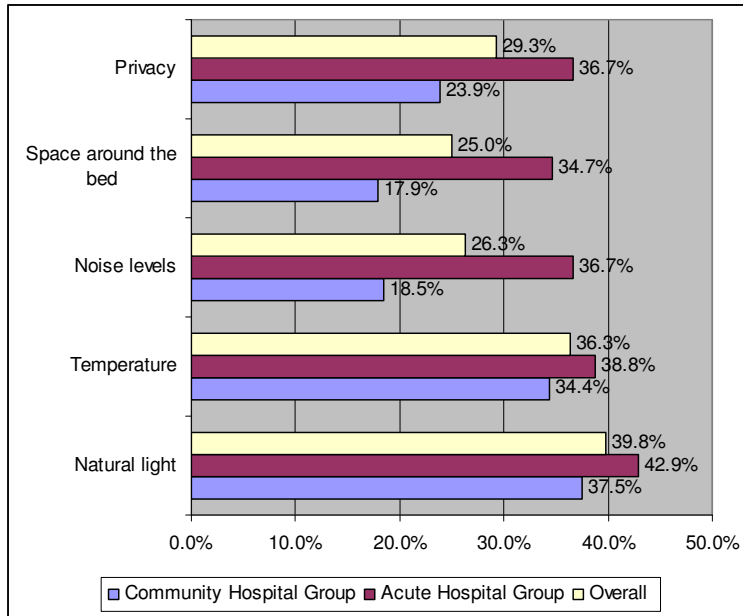
Table 33: Respondents' views regarding type of room the patient died in.

	Overall		Acute Hospitals		Community Hospitals	
	N	%	N	%	N	%
<i>During your relative's last stay in hospital, did hospital staff offer her a choice of room (e.g. single room or ward)?</i>						
Yes	26	22.6	12	24.5	14	21.2
No	72	62.6	33	67.3	39	59.1
Don't know	17	14.8	4	8.2	13	19.7
<i>In what type of room did your relative die?</i>						
Single room	30	25.4	16	32.0	14	20.6
Ward	75	63.6	22	44.0	53	77.9
Special unit	11	9.3	11	22.0	0	0
Other room	2	1.7	1	2.0	1	1.5
<i>Would your relative have preferred a single room at this time?</i>						
Yes	24	27.6	10	30.3	14	25.9
No	32	36.8	11	33.3	21	38.9
Don't know	31	35.6	12	36.4	19	35.2
<i>Would you have preferred if your relative had died in a single room?</i>						
Yes	43	49.4	18	52.9	25	47.2
No	38	43.7	12	35.3	26	49.1
Don't know	6	6.9	4	11.8	2	3.8

Physical Environment

Respondents also rated aspects of the physical environment. Figure 11 describes the percentage of respondents who gave each aspect an "excellent" rating. Overall between 25.0% and 39.8% rated each aspect as excellent, natural light was rated as excellent most often and space around the bed was rated as excellent least often.

Figure 11: Percentage of respondents who provided an “excellent” rating to aspects of the physical environment.

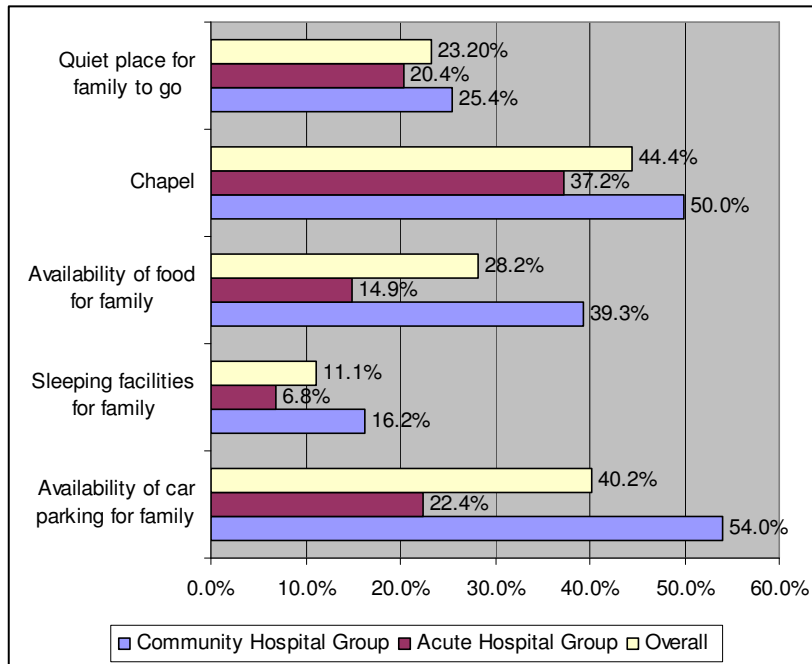


A higher percentage of respondents in the acute hospital group than in the community hospital group rated the five aspects as excellent. The highest discrepancy between acute and community ratings were in relation to noise levels (18.2%), space around the bed (16.8%) and privacy (12.8%).

Hospital Facilities

Respondents also rated the hospital facilities. Figure 12 describes the percentage of respondents who gave an excellent rating for a range of hospital facilities. Overall between 11.1% and 44.4% rated the hospital facilities as excellent. The chapel was most often rated as excellent and sleeping facilities for family were least often rated as excellent. More respondents in the community hospital group than the acute hospital group rated each of the five aspects of hospitals facilities as excellent. The highest discrepancy between community and acute ratings were in relation to availability of car parking for family (31.6%), availability of food for family (24.4%) and the Chapel (12.8%).

Figure 12: Percentage of respondents who provided an “excellent” rating for hospital facilities.



Respondents also commented on the environment of care when they were asked to describe “care that was satisfactory” and “care that could have been done better”. Seven respondents whom were from the acute hospital group provided positive comments on the environment of care. However, over two thirds (n=24; 66.7%) of those who provided comments on “care that could have been done better” described aspects of the environment of care that could have been improved. These represented over half (n=13; 56.5%) of those who provided comments in the acute hospital group and the majority (n=11; 84.6%) of those who provided comments in the community hospital group.

Respondents commented on three core issues. The first issue concerned the provision of privacy and dignity for the patient and family during the dying experience. While some patients and families were provided with single rooms at the time of dying, more often than not respondents were dissatisfied with the lack of privacy due to the insufficient availability of single rooms for patients while dying. This was reported to be distressing not only for patients and families but for other patients on the wards. The second issue concerned the quality of the physical environment. Some respondents reported that the general surroundings could be improved for example, space in rooms and wards, curtains and bedding. The third issue related to facilities. For example, some respondents felt

there was a need to provide family rooms for grieving and better overnight stay facilities and to increase the flexibility of visiting times. A selection of respondents' comments is provided next.

Table 34: Care that was satisfactory – privacy and dignity

Community Hospital Group

“On the morning he died, the hospital rang me to come in. No single room was available. The other patients were brought to a day room and we were given the privacy and help. I could not give enough praise for what I seen for the time my father went to [this] Hospital.”

Acute Hospital Group

“As she deteriorated a side room was made available quite promptly. After death there was no rush to mortuary allowing family to travel & spend time with my mum in private.”

“A private room was granted in which to spend her last days. A lady pastor visited and said beautiful prayers. The room was very serene with a nice view from the window.”

“The day before my mother died, a single room became available on the ward. The staff cleaned the room from top to bottom and moved my mother into it the day before she died. This meant a great deal to us all and allowed my mother great dignity at the end. I don’t think she could have been cared for any better they were tremendous.”

Table 35: Care that could have been done better – privacy & dignity

Community Hospital Group

“The only problem I would have found was there was no single room available during the last few days before she passed away. This was not the fault of the staff.”

“The only thing that upset me at the time of my father’s death about the hospital care was the lack of privacy – the nurses kept apologising about this but they just did not have a private room available where we could go with our father as he died – I feel he was robbed of his dignity at the final stage of his life – and it wasn’t fair on the other patients in the ward either.”

Acute Hospital Group

“When patients are ready to die, they should not be left in a ward with other patients. It is very upsetting for them. One old lady said to me “I suppose I will be next”.

“My husband died a few hours later while the TV was still on and visitors coming and going, we requested a room and none was available. ”

“The death in a ward in daylight hours was trying. Both of us needed privacy and extra care at that time. I was too upset to leave or ask for this. This needs to be forthcoming.”

“I thought that the immediate removal of all the supportive equipment was very clinical (within moments of his death, all plugs unplugged, cables coiled, trolleys pushed out – a flurry of activity)– understandable in these times but almost factory like.”

Table 36: Care that could have been done better - physical environment

Community Hospital Group

“I know that there are budgetary constraints to the money received but if more could be spent on the surroundings, eg. curtains, bed clothes and especially private rooms for when people are dying.”

“Space in wards could be improved.”

Table 37: Care that could have been done better - hospital facilities

Community Hospital Group

“Better family rooms for grieving. Better overnight stay facility. Better care taken of personal belongings of patient.”

Acute Hospital Group

“No place for relatives to rest. No food, ie. Meals, available – had to leave hospital (snacks available until 8:30pm). Poor ventilation/space.”

“Visiting times very rigid – didn’t accommodate visitors of a dying person who had to work in non nine to five jobs.”

5.5.5 Care Outcomes

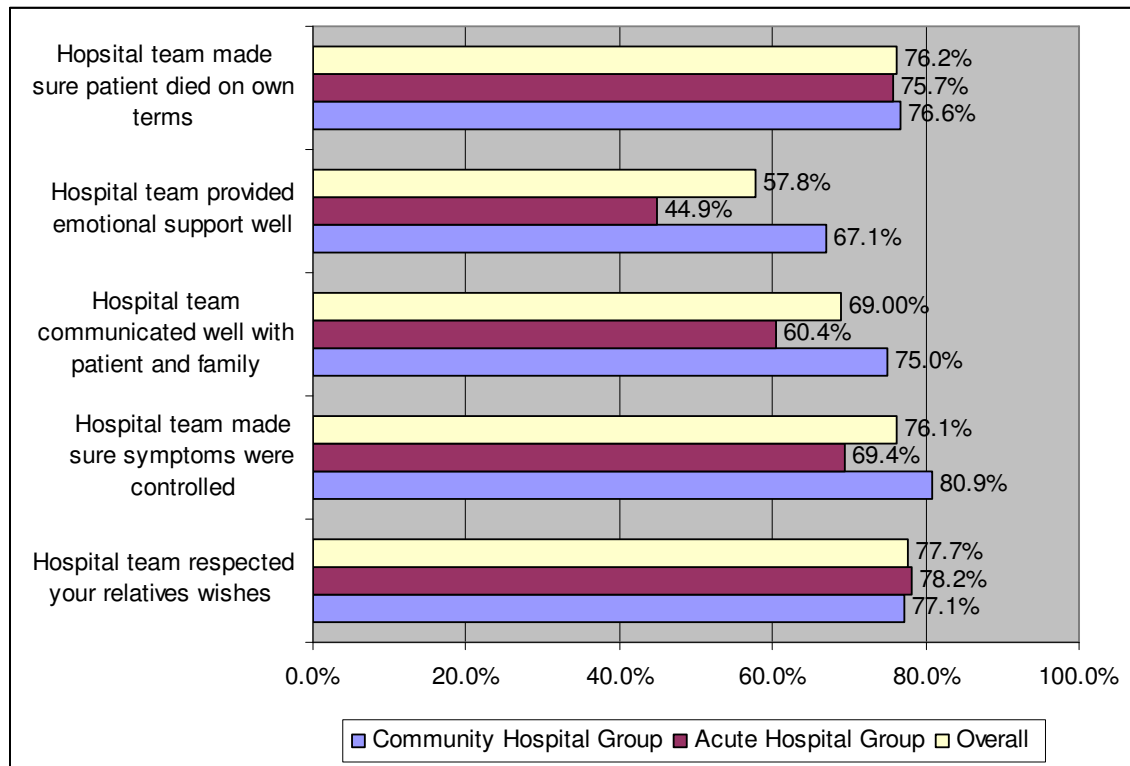
The care outcomes assessed by the survey included respondents’ overall satisfaction with care and views of the overall quality of care.

5.5.5.1 Overall satisfaction domain

Respondents were asked to rate the five aspects of end-of-life care using a 0-10 response task, where 0 is the worst possible care and 10 is the best possible care. For this domain, ratings from each of the five questions were averaged to generate a composite score that ranged from 0 to 50. The overall satisfaction score for hospitals overall was 43.1. The overall satisfaction score for the community hospital group (44.7) was higher than the score for the acute hospital group (40.6).

In addition, Figure 13 details the proportion of respondents who provided a rating of best care (9 or 10).

Figure 13: Relatives “best rating (9 or 10)” of aspects of end-of-life care.



High performance areas (over 75% best rating (9 or 10) on satisfaction scale) across all groups were making sure the patient died on their own terms and respecting the patient’s wishes. Low performance areas across all groups included the provision of emotional support and communicating well with the patient and family. Making sure that symptoms were controlled to a degree that was acceptable to the patient was a low performance in the acute hospital group but a high performance area in the community hospital group.

5.5.5.2 Overall quality of care

Respondents rated the overall quality of care during the patient’s last hospital stay. The quantitative findings as well as the qualitative data which described the professionalism of staff are presented next.

Overall, approximately 60% of respondents rated the overall care received by the patient as “excellent”, representing a 40% opportunity to improve care. The opportunity to improve care was 45.8% in the acute hospital group and 36.9% in the community hospital group.

Respondents rated the care received at evenings and weekend less well in comparison to overall care. Overall, approximately 41.2% rated care at evenings and weekends as “excellent” and this figure was 29.2% in the acute hospital group and 50% in the community hospital group.

Table 38: Overall Quality of Care

	Overall		Acute Hospitals		Community Hospitals	
	N	%	N	%	N	%
<i>Overall how would you rate the care your relative received while in hospital?</i>						
Excellent	67	59.3	26	54.2	41	63.1
Very Good	30	26.5	10	20.8	20	30.8
Good	10	8.8	8	16.7	2	3.1
Fair	4	3.5	2	4.2	2	3.1
Poor	2	1.8	2	4.2	0	0
<i>How would you rate the way the hospital team responded to your needs in the evenings and the weekends?</i>						
Excellent	47	41.2	14	29.2	33	50.0
Very Good	36	31.6	15	31.3	21	31.8
Good	17	14.9	10	20.8	7	10.6
Fair	7	6.1	5	10.4	2	3.0
Poor	4	3.5	2	4.2	2	3.0
Never contacted evening or weekend services	3	2.6	2	4.2	1	1.5
<i>Based on the care your relative received would you recommend hospital services to others?</i>						
Yes	107	93.9	43	89.6	64	97.0
No	7	6.1	5	10.4	2	3.0

Overall the majority (93.9%) indicated that they would recommend the hospital services to others. This figure was higher in the community hospital group (97.0%) than in the acute hospital group (89.6%).

Of the respondents who provided comments on “care that was satisfactory” (n=64), the majority (n=53; 82.8%) described the professionalism of hospital staff. This represented three quarters of respondents (n=24; 75.0%) who provided comments in the acute hospital group and the majority (n=29; 90.6%) of respondents who provided comments in the community hospital group. Common sub-themes included the excellence of the care provided; the kind, respectful, empathetic and caring nature of staff

as well as their welcoming approach towards families visiting. A selection of respondents' comments is provided next.

Table 39: Care the was Satisfactory – Professionalism of Staff

Community Hospital Group

"I visited my aunt in Hospital everyday for almost 4 years. The care and kindness she received from both nurses & ward staff was excellent & when my time comes I would have no problem in ending my days there."

"Care was always to the highest standard and there was a lovely friendly and homely atmosphere from all members of staff. The best care that could be given, was given at all times."

"I found the nursing, carers and all staff excellent in looking after my mam, they done everything for her, making her feel comfortable, and that she was being treated with respect and dignity."

"The care was excellent, the staff were the best people I ever met and worked very hard. They do a very hard job both physically and emotionally. I hope that if the time ever comes that I need this type of care I will be lucky enough to meet people like those people that looked after my uncle."

Acute Hospital Group

"My husband spent two days in the coronary care unit where the nurses couldn't do enough for him. Three days in ICU cared for by a very kind nurse. Doctors did everything they could and were very kind, my husband was treated with respect."

"At all times when our dad was ill we were treated with the utmost of care and sensitivity for which we are all very grateful. It was a very difficult time for us all and we can have no complaints about his care."

"My mother was very well cared for in the hospital. The staff looked after her every need and respected her every wish. They were very good to my Dad also. They even came to visit him some time after my mother's death to see how he was coping and how he was getting on."

"I believe the care and attention shown to my brother, the deceased and to me and my family were second to none at a time that was very trying for us. The dignity, professionalism, care and attention could not be matched anywhere."

"I could not rate all staff i.e. doctors, nurses, attendants and carers highly enough. Everyone was so kind to my Dad. The doctor's did all they could."

"We cannot speak highly enough of the care our relative received in the ICU. From doctors down to the daily and night nurses, they were so professional and caring."

5.6 Discussion

This section identifies the survey of bereaved relatives' core findings and discusses these in the context of the literature on end-of-life care and HfH Programme themes. The first part of the discussion is relevant to the methodology of evaluating end-of-life care and the second part examines the survey findings relevant to each HfH Programme theme; patient autonomy, integrated care, communication and design & dignity.

5.6.1 Retrospective Surveys of End-of-Life Care as a Research Methodology

The following key findings which concern the methodology of evaluating end-of-life care are important to consider in planning methods to evaluate the quality of end-of-life care provided to patients and families.

Key Finding One: Conducting postal surveys of bereaved relatives is an acceptable means of evaluating the quality of end-of-life care in Ireland.

This pilot study has established that conducting postal surveys of bereaved relatives is an acceptable means of evaluating end-of-life care in Ireland. This is evidenced by two factors. Firstly, almost 40% of those contacted consented to receive the questionnaire and this rate of consent was within the range of the consent rate (50.5%) achieved in a Welsh study that utilized a similar two step approach to obtaining consent and survey responses (Ingleton et al., 2004). Secondly, the study achieved good response rates. The study achieved a 31.6% response rate, expressed as a percentage of those contacted and an 83.1% response rate, expressed as a percentage of those who consented to receive the survey also. The response rates were similar to those achieved by the similarly modelled Welsh study; the respective response rates were 37% and 74% (Ingleton et al., 2004). Other Irish (Walsh et al., 2007, Vincents et al., 2007, McKeown et al., 2010) and international end-of-life care studies (Connor et al., 2005) who combined obtaining consent and postal responses simultaneously, or whom preceded postal contact with verbal consent, achieved response rates of 40%, 54%, 46% and 45% respectively.

Key Finding Two: Patient, contact person and hospital factors had an impact on likelihood to consent to receive the questionnaire.

Those who were more likely to consent to receive the questionnaire were contact persons of deceased males, female contact persons and contact persons of patients who died in community hospitals. For example, a higher number of contact persons of deceased males (40.9%) than of deceased females (35.1%) consented. The consent rate from female contact persons (n=209) was 45.5% compared to 28.4% from male contact persons (n=165). There was a higher consent rate from contact persons of deceased patients who died in community hospitals (44.2%) than from contact persons of those who died in the acute hospital group (31.1%). These findings are important as they create a profile of people who are less likely to consent to receive a postal questionnaire to evaluate end-of-life care. The findings present useful information for researchers and policy makers to consider in designing end-of-life care evaluations. The challenge is to ensure that the evaluation designs employed entice the range of profiles of respondents to participate in the research. To this end, perhaps a range of methodological approaches are required within studies.

Key Finding Three: Timing between bereavement and research contact had an impact on consent rates.

The highest proportion of contact persons consented to receive the questionnaire when they had been bereaved for 13-18 months and this finding applied to both the acute and community hospital groups. While an Italian study that used in-depth interviews found that response rates decreased with an increasing time after the patient's death (Constantini et al., 2005), this Irish study found rates of consent to receive the questionnaire were higher between 13 – 24 months (47.1%) than at 5 – 12 months (30.6%). It is also noteworthy that two similar studies conducted in Ireland (Walsh et al., 2007, Vincents et al., 2007) did not contact relatives until at least one year of bereavement. However a recent national audit of end-of-life care in Ireland contacted relatives after three months of bereavement and achieved comparable response rates (46%) (McKeown et al., 2010). Considering the research studies collectively, it can be suggested that there is no “rule of thumb” regarding the appropriate time frame after bereavement to contact relatives regarding research, rather this is based on individual preferences. The results of this study suggest that in Ireland, perhaps longer time frames between bereavement and research contact are preferable to most potential respondents.

From the point of view of achieving the maximum number of responses, these findings are important to consider in planning the appropriate time interval after the patient's death to contact bereaved relatives regarding participating in research.

5.6.2 Impact of Deceased Patients and Respondent Attributes on Interpretation of the Research Findings

It has been demonstrated in the literature that patient and bereaved relative attributes impact relatives' evaluations of end-of-life care (Fakhoury et al., 1996). The implications of the profile of patients and respondents for interpreting the research findings are discussed in the key findings next.

Key Finding Four: The profile of respondents differed among acute and community groups by age.

While in both the acute and community hospital groups, approximately two thirds of respondents were female (68.0%, 65.7%) and were immediate family members – spouse/partner, son/daughter, brother/sister (90%, 77.2%), the age profile of respondents was younger in the acute hospital group than in the community hospital group. One in five was aged over 65 years in the acute hospital group in comparison to one in three in the community hospital group. This finding is important to consider in interpreting the research findings and comparing the two groups. It has been reported that older populations are more likely to report socially desirable responses due to more stoical attitudes than younger age groups (Addington-Hall., 1998) and it is difficult to ascertain if these responses are an accurate reflection of the care provided. For example, Fakhoury et al. (1996) showed that informal carers satisfaction with the care delivered to dying people in the last year of life is predicted by carer attributes. While sex had no significant association with satisfaction, informal carers who were aged 65 years or over were significantly more likely than others to be highly satisfied.

Key Finding Five: While patients in the acute and community hospital groups died of similar illnesses, their age profile and length of last hospital stay differed between the hospital groups.

Overall, the top four leading causes of death were cancers (24.8%), lung and breathing diseases (20.5%), frailty and decline due to old age (15.4%) and heart and circulatory diseases (14.5%). These were similar across both hospital groups, however frailty and decline due to old age was not commonly cited as a cause of death in the acute hospital group. The profile of cause of death is similar to the profile outlined in the National Audit of End-of-Life Care in Ireland. The three main causes of death among patients in the audit were circulatory (31%), cancer (23%) and respiratory (19%) (McKeown et al., 2010). The audit described a hierarchy of dying based on patient's disease. The range from best to worst, was cancer, circulatory diseases, respiratory diseases and dementia/frailty. The reasons for this were not attributable to characteristics of the diseases but to other factors. For example, patients dying of cancer were more likely to have planned admissions, greater likelihood of dying in a single room, better communication, more team meetings, and more support for families to stay overnight and be present at the moment of death (McKeown et al., 2010).

As with respondents, the age profile of deceased patients was younger in the acute hospital group than in the community hospital group. Two out of three patients were aged over 75 in the acute hospital group compared to nine out of ten patients in the community hospital group. In spite of these differences, research studies have found that age of the patient is not an important predictor of informal caregiver satisfaction with end-of-life care (Fakhoury et al., 1996) or of the quality of end-of-life care (McKeown et al., 2010).

The most common lengths of last hospital stay were 3-14 days (66.7%) in the acute hospital group compared to 1-6 months (56.9%) in the community hospital groups. These findings are important to consider when comparing data about the quality of end-of-life care in acute and community hospitals. For example, the fact that patients tend to have a longer length of stay in the community hospitals may mean that patients have an increased chance of receiving good quality care as hospital staff have a longer time frame to become familiar with the patients' condition and their care needs. In addition, relatives of patients have a longer time frame to establish rapport with hospital staff and to interact

regarding patients' care needs. This too may mean that relatives of patients in community hospitals may rate the quality of end-of-life care better than relatives of patients who died in acute hospitals. These findings are particularly important to consider in this study given that in this study's methodology, respondents completed survey questions based on the length of the patient's last hospital stay, rather than the last few days of life or last week of life. However, albeit in a hospice setting, one study did find that bereaved family member perceptions of the quality of end-of-life care did not vary by length of stay for each of the Family Evaluation of Hospice Care questionnaire domains (Teno et al., 2007). Further research and analysis is required to assess the impact of length of last hospital stay on care-giver evaluation.

5.6.3 Implications of Survey Findings for HfH Theme Patient Autonomy

The focus of HfH Programme activities in the area of patient autonomy is on the rights of patients and on the importance of an ethical framework which supports hospital staff to become more informed, confident and collaborative in addressing the ethical and legal challenges that arise in the treatment and care of dying patients and their families (McKeown et al., 2010). Sub-themes measured by this study include advanced care planning – treatment preferences and preferences for dying at home.

Key Finding Six: While respondents in both acute and community hospital groups did not identify a problem with hospital care that was inconsistent with patients' previously stated wishes, findings identified a need for increased discussion, between the patient, family and hospital staff regarding patients' medical wishes for end-of-life care.

The domain score for "provide patient autonomy" was similar across the acute (72.4%) and community (71.1%) hospital groups, reflecting largely positive evaluations for this domain of care. While over 90% of respondents in both groups were confident that hospital staff did not do anything inconsistent with patients' previously stated wishes, only approximately half of respondents reported that hospital staff spoke to the patient and/or family regarding their wishes for medical treatment while dying. This finding may be a reflection of the underdevelopment of advance care planning for end-of-life care in Ireland to date. This finding provides further supporting evidence of the

importance of implementing the HfH Programme activities that facilitate patients' right to autonomy. From the point of view of healthcare providers, this study finding underlies the importance of utilizing ethical frameworks which support hospital staff to become more informed, confident and collaborative in addressing the ethical and legal challenges that arise in the treatment and dying of patients and their families (McKeown et al., 2010). Consistent use of such frameworks would enable dying patients and their families become more involved in decision-making at end-of-life and to make their preferences regarding end-of-life care to become known.

Key Finding Seven: Approximately one in ten respondents in the community hospital group compared to one in four in the acute hospital group felt that the hospital was not the right place for the patient to die given their needs in their final days.

This finding implies that there is more dissatisfaction among respondents in acute hospital group regarding the suitability of the hospital as the place of death given the needs of dying patients. Of those whose preferences were not met, overall the preferred place of death was home (50%), hospices (25%) or other facilities (25%) such as nursing homes. Other studies have identified unmet needs regarding facilitating patient and family preferences regarding dying at home (Beccaro et al., 2006; Ingleton et al., 2004; McCarthy et al., 1997). According to McKeown et al (2010) whether a patient could have died at home, or would have preferred to die at home, has no distinct effect on care outcomes such as acceptability of the way the patient died, quality of patient care, patients symptom experience, patients symptom management and support for patient's family. However from a patient autonomy and economic perspective, facilitating preferences for dying at home is important. It has been estimated that up to €80 million could be made available for end-of-life care if 22% of patients died at home rather than in acute hospitals (McKeown et al., 2010).

5.6.4 Implications of Survey Findings for HfH Theme Integrated Care

The focus of HfH Programme activities in the area of integrated care is to promote a more seamless, holistic and user-friendly care for the dying person and his or her family (McKeown et al., 2010). Sub-themes measured by this study include symptom control, symptom experience, spiritual well-being, psycho-social supports, continuity of care and

relatives' care of the patient. Key findings relevant to the theme of integrated care are discussed next.

Key Finding Eight: Both respondents in the acute and community hospital groups rated the provision of physical comfort for pain and for trouble with breathing similarly. However patients needs for help with feelings of anxiety and sadness appeared to be met better in the community hospital group than in the acute hospital group.

Similar proportions of respondents in the acute and community hospital groups respectively reported that patients had pain (83.7%, 82.1%) and had feelings of anxiety and sadness (64.6%, 59.1%) during the last hospital stay. While most respondents (80%) in the acute hospital group reported that the patient had trouble with breathing during the last hospital stay, this figure was under half (47.8%) in the community hospital group. Approximately 90% of respondents across groups felt the patient received the right amount of help for pain and trouble with breathing. However, there was more unmet need for help with patient's feelings of anxiety/sadness in the acute hospital group than in the community hospital group. The unmet need scores for help with feelings of anxiety and sadness were 51.9% in the acute hospital group and 15% in the community hospital group. From the point of view of emotional wellbeing and comfort, this represents a large discrepancy in the patient's experience of dying between acute and community hospitals.

The validity of these findings is strengthened when considered in the context of the literature. Family members are more likely to over report pain severity in comparison to patients (Fowler et al., 1999) whereas patients' prospective and relatives' retrospective accounts of dyspnea and anxiety have been shown to be moderate or substantial (Hinton 1996 cited in Teno 2005). Therefore addressing the unmet needs for help with anxiety and sadness, in acute hospitals in particular, can be viewed as a priority area for action within the activities of the HfH Programme.

Key Finding Nine: The domain score for attending to family needs for religious and emotional support was higher in the community hospital group (76.3%) than in the acute hospital group (64.3%). Respondents in both groups valued when support was provided to both the patient and the family.

In less than 40% of cases across groups, hospital staff discussed the religious or spiritual beliefs of family members with them. However overall 85.1% of respondents felt they had the right amount of contact regarding their religious and spiritual beliefs as they wanted. Approximately three in four respondents in the acute hospital group and over four in five respondents in the community hospital group indicated they had the right amount of religious/spiritual contact with hospital staff and that they received the right amount of emotional support from hospital staff both prior to and after the death.

Qualitative data showed that respondents valued when support was provided to both the patient and the family, as the unit of care. These findings indicate that while there are opportunities for improvement, hospital staff seem to be meeting *family* needs for emotional and religious support in most cases. The opportunity to improve care in this domain was 23.7% in the community hospital group and 35.7% in the acute hospital group.

When compared to some other findings in this study, it would appear that healthcare professionals in acute hospitals are better positioned to meet the emotional needs of family members than those of dying patients. As discussed previously, this study found, based on respondent reports, a large amount of unmet need for help with feelings or anxiety and sadness among dying patients in the acute hospital group. The National Audit of End-of-Life Care identified that the reasons for this pattern of communication may include: the difficulties of communicating with patients whom are dying, a tendency among healthcare professionals to speak with families of older people rather than the older person, the difficulties healthcare professionals may have in speaking about death and dying and the fear of complaints from relatives which are unlikely from dying patients (McKeown et al., 2010). Given the difficulties of communication with patients at the end-of-life, attention needs to be paid to developing means to providing the emotional support patients may need at this time. Part of this may involve improving staff awareness and skills in the range of communication skills needed in providing end-of-life care.

Key Finding Ten: Domains scores for providing co-ordination of care were higher in the community hospital group (80.9%) than in the acute hospital group (63.3%). Across both groups the highest opportunity to improve care was with regard to having one nurse identified as in charge of patient care.

The community hospital group performed better than the acute hospital group with regard to the three items across the provide co-ordination of care domain. For example, reporting the community hospital finding first, higher scores were achieved in regard to the hospital never giving confusing or contradictory information about the relative's medical treatment (83%, 66%); always having one nurse identified as in charge of patient care (69.1%, 46.9%) and not having any problem with the hospital team not knowing enough about the patient's medical history (89.7%, 77.1%). The qualitative data highlighted some further opportunities to improve care in relation to the acute hospital group. This concerned for example remedying delays in hospital admission, insufficient communication between hospital teams, insufficient care at weekends and inappropriate delays in implementing decision-making regarding care. The opportunities to improve care in the co-ordination of care domain were 36.7% in the acute hospital group and 19.1% in the community hospital group.

These findings support the need for utilization of integrated care pathways in providing end-of-life care. Overall the pathways provide a structure for both educating health care providers and performing clinical services (Fineberg and Hughes, 2007). In addition to other benefits, pathways offer means for documenting whether aspects of care are provided and in addition to the patient's file provide a concise history of the care provided. The implementation of pathways supports an inter-disciplinary team approach to patient care and through accessible and auditable documentation support quality assurance mechanisms. They may be helpful for improving the co-ordination of end-of-life care. The National Audit of End-of-Life Care in Ireland supported the notion of improving patient documentation. The audit noted that documentation is essential to supporting a consistent approach to patient care across the hospital team and other studies have found it to be a good indicator of quality of care (McKeown et al., 2010).

5.6.5 Implications of Survey Findings for HfH Theme Communication

The HfH Programme theme communication involves activities aimed at enhancing the skills of staff to relate simply and warmly to patients while respecting their autonomy and preferences (McKeown et al., 2010). Sub-themes measured by this study include breaking bad news, provision of information on patient's medical treatment, provision of information on supports for family, provision of information on the patient's condition, provision of information for family members on what to expect while the patient is dying and the patients' awareness of dying.

Key Finding Eleven: Domains scores for attending to family needs for information were higher in the community hospital group than in the acute hospital group. Areas most frequently identified for improvement were the provision of information on the dying process and on pain management.

The findings identified a need for better information provision regarding what to expect while the patient is dying. While similar numbers of relatives in the acute (54.2%) and community (61.2%) hospital groups indicated that they had received *information on what to expect while their relative was dying*, most (80.3%) in the community hospital group were satisfied with the amount of information they had received compared to two thirds (64.6%) in the acute hospital group.

Respondents in both groups similarly rated the provision of information on breathing problems; overall 70% had received information on treatment for breathing problems with 81.9% being satisfied with the level of information they received. However, over three quarters in the community hospital group compared to two thirds in the acute hospital group reported they had received information on pain management medication. Most (92.9%) in the community hospital group compared to 73.2% in the acute hospital group were satisfied with the amount of information they had received.

Perhaps improving provision of information to families, would improve confidence of family members who are involved in providing care to dying patients while they are in hospital. This study found that half of respondents (52.1%) were involved in providing

care to patients while they were dying and of these, half were very confident in doing what they needed to do in taking care of their relative.

The provision of information to relatives is also important when viewed from the perspective of care outcomes. The National Audit of End-of-Life Care in Irish hospitals found that the quality of communication with relatives is an important determinant of care outcomes (McKeown et al., 2010). The audit found that care outcomes are influenced by the quality of discussion with patients and relatives, not by the amount of discussion. Of equal importance the audit found that care outcomes are influenced more by the quality of discussion with relatives than with patients (McKeown et al., 2010). This study found that providing information on what to expect while the patient is dying and on pain management are priority areas for action.

Key Finding Twelve: Across groups, of respondents who were told the patient was likely to die soon, the vast majority (91.2%) reported that this was done in a sensitive way, however three in ten respondents reported that there was not enough privacy at this time. A higher proportion of relatives in the community hospital group (92.6%) than in the acute hospital group (74.0%) reported that they felt prepared for the death.

These findings regarding evaluations of breaking bad news are similar to those found in other Irish studies. For example, Keegan et al (1999) in a Care for the Dying study found that 73% positively evaluated the way they were told the prognosis of dying. However areas for improvement across both studies included the importance of having privacy at this time. It is also important that families are afforded the opportunity to understand what is happening to their ill relatives so as to adjust to their impending loss (Vincent's Palliative Care Group, 2007). Findings underlying the importance of this include that of those who felt "very prepared" for the death of the patient, 88.3% had been told by the hospital team that their relative was likely to die soon; of those who felt "somewhat prepared" for the death 68.5% had been told by the hospital team that their relative was likely to die soon and the figure for this in the "not at all prepared" category was 66.6%.

Key Finding Thirteen: Across groups, based on respondent reports, approximately 40% of patients were aware that they were dying. However family members and hospital staff told the patient that they were likely to die soon in less than 20% of cases across groups. Approximately one third of respondents in the acute hospital group and one quarter of respondents in the community hospital group felt the patient would have liked to have known that they were likely to die soon.

The findings regarding the prevalence of awareness of death among patients is similar to that found in a UK study (50%) (McCarthy et al., 1997) but less than that in another Irish study (69%) (Keegan et al, 1999). The findings in the context of this study reflect a certain level of discomfort regarding discussing death with the patients and are perhaps linked to hospital and relative perceptions that most patients would prefer not to know when they are going to die. However, to ascertain if patients would like to know use of the ethical framework for discussing death with patients are relevant here.

5.6.6 Implications of Survey Findings for HfH Theme Design & Dignity

The focus of activities for the HfH Programme Theme Design & Dignity is on providing peaceful and dignified surroundings which ensure the patient's dignity and privacy, and offer a sense of psychological and spiritual support (McKeown et al., 2010). The Design and Dignity theme can be described as how the design and configuration of hospital facilities support a sense of dignity and privacy around dying in hospital (Hugodot and Normand, 2007). Sub-themes measured by this study include respect/dignity, place of death, privacy, environment of death and family presence at time of death.

Key Finding Fourteen: There were more opportunities to improve care in relation to the provision of dignity and respect in the acute hospital group than in the community hospital group.

Two thirds of respondents in the acute hospital group indicated that the patients personal care needs were “always” taken care of as well as they should have been by the hospital team in comparison to 83.8% of respondents in the community hospital group.

Key Finding Fifteen: Overall, while over 90% of respondents would like to have been present at the time of death, approximately half were actually present at this time in the community hospital group and nearly two thirds were present in the acute hospital group. Opportunities for improvement are in regard to hospital staff arranging to facilitate family presence at the time of death.

Difficulties associated with facilitating family preferences to be present at the time of death include the unpredictability of the time of death and the ability of relatives to arrive to the hospital before the time of death. However what is in the control of healthcare professionals is whether relatives are asked if they would like to be present at the time of death and whether appropriate information is obtained for making contact with relatives at such times. This study's findings represented opportunities for improvement in this area. In the acute hospital group, approximately half of respondents (53.1%) reported that hospital staff asked them if they wished to be present at the time of death and this figure was nearly two thirds (63.6%) in the community hospital group. Other studies have found that of relatives who have been present at the time of death, the vast majority were glad to have been there (Keegan et al., 1999).

Key Finding Sixteen: Patients were more likely to die in a single room if they died in an acute hospital, one in three died in a single room in the acute hospital group, compared to one in five in the community hospital group. Qualitative findings indicated that the lack of availability of single rooms at the time of death, led to insufficient privacy and dignity for the patient and families and was distressing for other patients on the ward.

These findings are similar to those found in the national audit of end-of-life care in Ireland. The audit reported that a third of patients (33%) spent most of their last week in a single room, and more than four in ten (44%) died in a single room (McKeown et al., 2010). While hospital staff often provide single rooms at the time of dying to facilitate privacy and dignity, the lack of availability of these means there is a significant amount of unmet need remains (McKeown et al., 2010). The qualitative findings of this study indicate that relatives do not blame staff for this and are aware that this is a hospital resource limitation. This study's findings suggest that the unmet need is largest in community than acute hospitals.

From the point of view of care outcomes, facilitating patient preferences regarding type of room is very important. The audit found that deaths in single rooms are associated in a statistically significant way with substantially better care outcomes, when compared with larger occupancy rooms. From the perspectives of relatives and healthcare professionals, the audit found that the acceptability of the patient's death is much higher in single rooms and symptom management and experience are better (McKeown et al., 2010).

This study adds that part of the problem in ascertaining patient preferences for type of room at end-of-life is that across groups less than one in four patients were offered a choice of room and at least one in three respondents were unaware of patient preferences at this time. Across groups, approximately 50% of respondents would have preferred if the patient had died in a single room. These findings demonstrate the need for greater discussion between all relevant stakeholders regarding preferences for end-of-life care – clearly choice of type of room needs to be included in this discussion. Based on a review of the literature on HfH Theme Design and Dignity, Hugodot and Normand (2007) have argued that each individual should have a choice in the type of accommodation they prefer. The findings of this review indicated that there should be an equal or greater number of beds in single rooms to shared rooms with community spaces which can meet the needs of those patients who require company. The review also indicated that adequate patient room size contribute to a perception of better amenities and greater privacy for care receivers during the admission and lessens their emotional and physical burdens (Hugodot and Normand, 2007).

Key Finding Seventeen: A higher proportion of respondents in the acute hospital group than in the community hospital group rated the *physical environment of the hospital* as excellent. Whereas a higher proportion of respondents in the community hospital group than in the acute hospital group rated the *hospital facilities* as excellent.

More respondents in the acute hospital group than community hospital group rated the physical environment as excellent in relation to space around the bed (by 16.8%), noise levels (by 18.2%), privacy (by 12.8%), temperature (by 4.4%) and natural light (by 5.4%). In contrast, more respondents in the community hospital group than acute hospital group rated the hospital facilities as excellent in relation to availability of car

parking for family (by 31.6%), availability of food for family (by 24.4%), chapel (by 12.8%), sleeping facilities for family (by 9.4%) and quiet place for family to go (by 5%). When considered in the context of the literature these findings provide important triggers for action. Research has shown that the physical environment of hospitals has an impact on care outcomes (Hugodot and Normand, 2007). The national audit of end-of-life care in Ireland found that the environment of the room or ward also has a significant influence on care outcomes. A percentage point improvement in the environment increases patient care by 0.80% for nurses and by 0.12% for doctors (McKeown et al., 2010). From the point of view of hospital facilities, it is important to improve relatives' experience of visiting dying patients by providing ease of access to hospital facilities such as car parking, food and sleeping facilities.

5.6.7 Implications of Survey Findings regarding Care Outcomes for HfH Programme Themes

The outcomes of care assessed by this study include overall satisfaction with care and overall quality of care. The key findings regarding these are outlined next.

Key Finding Eighteen: The satisfaction score for hospitals overall was 43.1. The overall satisfaction score for the community hospital group (44.7) was higher than the score for the acute hospital group (40.6).

High performance areas across both groups were *hospital team made sure patient died on own terms* and *hospital team respected the patients wishes*. Low performance areas in both groups were the *hospital team provided emotional support well* and *hospital team communicated well with patient and family*. The *hospital team making sure symptoms were controlled* was a low performance area in the acute hospital group but not in the community hospital group. The benefit of categorising areas into the high and low performance areas provides a means of prioritising areas for action.

Key Finding Nineteen: The rating of the overall quality of care and of care at the weekends was higher in the community hospital group than in the acute hospital group.

Nearly two thirds (63.1%) of respondents in the community hospital group rated the overall care the patient received while in hospital as “excellent”, in comparison to 54.2% of respondents in the acute hospital group. While 50% of respondents rated the way the hospital team responded to the patients needs in the evenings and weekends as “excellent” in the community hospital group, the figure for this in the acute hospital group was 29.2%. These findings underlie the needs for improvements in the co-ordination of care, in particular within the acute hospital group.

5.7 Conclusion

In conclusion, the presentation of the research findings has identified the pattern of results between the acute and community hospitals groups, focussing in particular on areas requiring improvement. The executive summary presents the recommendations arising from these.

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7 Appendix

7.1 Appendix One: Study Questionnaire



Family Evaluation of End-of-Life Care in Hospital

Please return questionnaire to:

Ms Siobhán McCarthy
Institute of Leadership and Healthcare Management
Royal College of Surgeons in Ireland
RCSI Reservoir House
Ballymoss Road
Sandyford
Dublin 18

Return by:

Day X Month Year



SURVEY OUTLINE:

- ❖ The results of this survey will be used to form a report about the quality of care of dying patients and their families in hospitals. The report will be used to help to improve quality of care at end-of-life.
- ❖ The survey is anonymous and no details which could identify individuals will be included in the report.
- ❖ The survey asks questions about end-of-life care in hospital. The questions are mainly about:
 - Decision making about care*
 - Symptom management*
 - Dignity and respect*
 - Communication with patient and family*
 - Emotional supports for patient and family*
 - Environment of care*
 - Quality of care*
- ❖ Some questions may be hard to answer because they remind you of a difficult time or bring up upsetting memories and feelings. Please feel free to skip questions you find too difficult to answer.
- ❖ Returned questionnaires will remain confidential to the research team at the Royal College of Surgeons in Ireland.
- ❖ Your participation is very much appreciated.

SURVEY INSTRUCTIONS:

- ❖ This questionnaire is best completed by the next of kin of the patient, or the person who was closest to and knows most about the care received by your relative while in hospital.
- ❖ Please answer each question by choosing the answer that best describes your experience and your relative's experience while under the care of the hospital.
- ❖ Please answer questions about the hospital care your relative received in relation to her ***last hospital stay***.
- ❖ Answer all the questions that apply to you by checking the box to the left of your answer or writing the information in the space provided.
- ❖ You are sometimes requested to skip over some questions. When this happens you will see an arrow with a note that tells you what question to answer next, like this:
 - ☐ Yes ☐ No → **If No, Go to Question B5**

SECTION A: DECISION MAKING ABOUT CARE

- A1) How long was the duration of your relative's last hospital admission? _____ ☐ days ☐ months
- A2) As far as you know, did any member of the hospital team speak to your relative or to a family member about her wishes for medical treatment when she was dying?
☐ Yes ☐ No ☐ Don't know
- A3) Did any member of the hospital team do anything with respect to end-of-life care that was inconsistent with your relative's previously stated wishes?
☐ Yes ☐ No ☐ Don't know

SECTION B: SYMPTOM MANAGEMENT

- B1) While in hospital, did your relative have pain or take medicine for pain?
☐ Yes ☐ No → **If No, Go to Question B5**
- B2) How much medicine did your relative receive for her pain?
☐ Less than she wanted ☐ Just the right amount ☐ More than she wanted
- B3) Did you or your family receive any information from the hospital team about the medicines that were used to manage your relative's pain?
☐ Yes ☐ No ☐ Don't Know
- B4) Did you want more information than you got about the medicines used to manage your relative's pain?
☐ Yes ☐ No
- B5) While in hospital, did your relative have trouble breathing?
☐ Yes ☐ No → **If No, Go to Question B9**
- B6) How much help in dealing with her breathing did your relative receive while in hospital?
☐ Less than she wanted ☐ Just the right amount ☐ More than she wanted
- B7) Did you or your family receive any information from the hospital team about what was being done to manage your relative's trouble with breathing?
☐ Yes ☐ No ☐ Don't Know ☐ No treatments used for breathing → **If no treatments used, go to Question B9**
- B8) Did you want more information than you got about what was being done for your relative's trouble with breathing?
☐ Yes ☐ No
- B9) While in hospital, did your relative have any feelings of anxiety or sadness?
☐ Yes ☐ No → **If No, Go to Question C1**
- B10) How much help in dealing with these feelings did your relative receive?
☐ Less than she wanted ☐ Right amount ☐ More help than she wanted

SECTION C: DIGNITY AND RESPECT

- C1) How often were your relative's personal care needs - such as bathing, dressing, and changing bedding - taken care of as well as they should have been by the hospital team?
- ☐ Always ☐ Usually ☐ Sometimes ☐ Never ☐ Only when requested ☐ Hospital team was not needed or wanted for personal care
- C2) How often did the hospital team treat your relative with respect?
- ☐ Always ☐ Usually ☐ Sometimes ☐ Never

SECTION D: COMMUNICATION

- D1) While your relative was in hospital, did you participate in taking care of her?
- ☐ Yes ☐ No → If No, Go to Question D5
- D2) Did you have enough instruction to do what was needed?
- ☐ Yes ☐ No
- D3) How confident did you feel about doing what you needed to do in taking care of your relative?
- ☐ Very confident ☐ Fairly confident ☐ Not confident
- D4) How confident were you that you knew as much as you needed to about the medicines being used to manage your relative's pain, shortness of breath, or other symptoms?
- ☐ Very confident ☐ Fairly confident ☐ Not confident
- D5) How often did the hospital team keep you or other family members informed about your relative's condition?
- ☐ Always ☐ Usually ☐ Sometimes ☐ Never ☐ Only when requested
- D6) Did you or your family receive any information from the hospital team about what to expect while your relative was dying?
- ☐ Yes ☐ No
- D7) Would you have wanted more information about what to expect while your relative was dying?
- ☐ Yes ☐ No

SECTION E: EMOTIONAL SUPPORTS

- E1) Did any member of the hospital team talk with you about your religious or spiritual beliefs?
☐ Yes ☐ No
- E2) Did you have as much contact of that kind as you wanted?
☐ Yes ☐ No
- E3) Do you feel that your relative's personal and religious beliefs were taken into consideration by hospital staff?
☐ Yes ☐ No ☐ Don't Know
- E4) How much emotional support did the hospital team provide to you prior to your relative's death?
☐ Less than was wanted ☐ Right amount ☐ More attention than was wanted
- E5) How much emotional support did the hospital team provide to you after your relative's death?
☐ Less than was wanted ☐ Right amount ☐ More attention than was wanted

SECTION F: CO-ORDINATION OF CARE

- F1) How often did someone from the hospital team give confusing or contradictory information about your relative's medical treatment?
☐ Always ☐ Usually ☐ Sometimes ☐ Never
- F2) While in hospital, was there always one nurse who was identified as being in charge of your relative's overall care?
☐ Yes ☐ No
- F3) Was there any problem with hospital doctors or nurses not knowing enough about your relative's medical history to provide the best possible care?
☐ Yes ☐ No

Please rate the following aspects of the care your relative received while under the care of the hospital. For questions F4 to F8, please use the scale from 0 to 10, where 0 means the worst possible care and 10 means the best care possible. Circle the number below each question that matches your response.

- F4) How well did the hospital team do at providing end-of-life medical care that respected your relative's wishes?

Worst care 0 1 2 3 4 5 6 7 8 9 10 **Best care**

F5) How well did the hospital team make sure that your relative's symptoms were controlled to a degree that was acceptable to her?

Worst care 0 1 2 3 4 5 6 7 8 9 10 **Best care**

F6) How well did the hospital team communicate with your relative and her family about the illness and the likely outcomes of care?

Worst care 0 1 2 3 4 5 6 7 8 9 10 **Best care**

F7) How well did the hospital team do at providing emotional support for you and your relative's family and friends?

Worst care 0 1 2 3 4 5 6 7 8 9 10 **Best care**

F8) How well did the hospital team make sure that your relative died on her own terms?

Worst care 0 1 2 3 4 5 6 7 8 9 10 **Best care**

SECTION G: AWARENESS OF DYING

We are aware that this section asks very sensitive questions. If you feel you can answer the questions, it will provide us with very valuable information for improving care in hospitals.

G1) Before the time of the death, did the hospital team tell you or another family member that your relative was likely to die soon?

☐ Yes ☐ No → If No, Go to Question G4

G2) Was this information shared in a sensitive way? ☐ Yes ☐ Somewhat ☐ No

G3) Was there enough privacy at this time? ☐ Yes ☐ Somewhat ☐ No

G4) How prepared did you feel for the death of your relative?

☐ Very prepared ☐ Somewhat prepared ☐ Not at all prepared

G5) Was your relative aware that she was dying? ☐ Yes ☐ No ☐ Don't know

G6) Do you think she would have wished to know? ☐ Yes ☐ No ☐ Don't know

G7) Did the hospital team tell your relative that she was likely to die soon?

☐ Yes ☐ No ☐ Don't Know

G8) Did you or any other family members/friends tell your relative that she was likely to die soon?

☐ Yes ☐ No ☐ Don't Know

SECTION H: FAMILY PRESENCE AT TIME OF DEATH

- H1) Did hospital staff ask you if you wished to be present at the time of the death? ☐ Yes ☐ No
- H2) Did you wish to be present at this time? ☐ Yes ☐ No
- H3) Were you actually present at this time? ☐ Yes ☐ No

SECTION I: ENVIRONMENT OF CARE

- I1) Considering your relative's needs in her final days, are you satisfied that the hospital was the right place for her to die? ☐ Yes ☐ No
- If no, where would you have considered most appropriate?
☐ Home ☐ Hospice ☐ Other, please write in: _____
- I2) During your relative's last stay in hospital, did hospital staff offer her a choice of room (e.g. single room or ward)?
☐ Yes ☐ No ☐ Don't Know
- I3) In what type of room, did your relative/friend die?
☐ Single Room ☐ Ward ☐ Special Unit (e.g. ICU) ☐ Other, please write in: _____
→If Single Room, Go to Question I6

- I4) Would your relative have preferred a single room at this time?
☐ Yes ☐ No ☐ Don't Know
- I5) Would you have preferred if your relative had died in a single room?
☐ Yes ☐ No ☐ Don't Know

- I6) Please rate your experience of the hospital physical environment, while your relative was dying:

Physical Environment:	Excellent	Very Good	Good	Fair	Poor
Privacy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Space around the bed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Noise levels	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Temperature	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Natural light	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- I7) Please rate your experience of the facilities within the hospital, while your relative was dying:

Hospital Facilities:	Excellent	Very Good	Good	Fair	Poor
Quiet place for family to go	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Chapel	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Availability of food for family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sleeping facilities for family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Availability of car parking for family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SECTION J: OVERALL QUALITY OF CARE

J1) Overall, how would you rate the care your relative received while in hospital?

☐ Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor

If you wish to do so, please comment on the care received:

Care that was satisfactory:

Care that could have been done better:

J2) How would you rate the way the hospital team responded to your needs in the evenings and weekends?

☐ Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor ☐ Never contacted evening or weekend services

J3) Based on the care your relative received, would you recommend hospital services to others?

☐ Yes ☐ No

SECTION K: ABOUT YOUR RELATIVE

Please tell us the following information about your relative:

- K1) What was your relative's age when she died? _____ years
- K2) Please choose the illness/disease that caused your relative's death. ***Please choose only one.***
- ☐ Frailty and decline due to old age ☐ Dementia & Alzheimer's disease ☐ Cancers - all types
 - ☐ Heart & circulatory diseases ☐ Lung & breathing diseases ☐ Kidney diseases
 - ☐ Liver diseases ☐ Strokes ☐ Infectious diseases
 - ☐ Another disease, please write in: _____

SECTION L: ABOUT YOU

Please tell us the following information about you:

- L1) How were you related to your relative who died?
- ☐ Spouse ☐ Partner ☐ Child ☐ Parent ☐ Sibling ☐ Other Relative ☐ Friend
 - ☐ Other, please write in: _____
- L2) How long has it been since you have been bereaved by the loss of this family member?
- Please write in _____ months _____ years
- L3) What is your age? _____
- L4) Are you male or female? ☐ Male ☐ Female

THANK YOU VERY MUCH FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE

Please feel welcome to contact us, if you would like to talk about your experiences and any of the questions on the questionnaire.

If you feel you need them, the contact details of bereavement support services are provided in the information leaflet you received with this questionnaire.

Thank you for helping us with this research. Your participation is very much appreciated.